



# Medical Sociology Study Group

48<sup>th</sup> Annual Conference Programme

7-9 September 2016  
Aston University, Birmingham

BRITISH  
SOCIOLOGICAL  
ASSOCIATION



# The British Sociological Association Annual Conference 2017

Tuesday 4 – Thursday 6 April 2017  
(Postgraduate Workshop – Monday 3 April)  
The University of Manchester

**Confirmed Plenary Speakers:** Ben Carrington, the University of Texas at Austin;  
Lynn Jamieson, the University of Edinburgh (BSA President); and Zoe Williams, Guardian  
Columnist

## Call for Papers

The British Sociological Association invites submissions to its Annual Conference. Participants can present on any sociological research topic.

Annual Conference 2017 Theme:

### Recovering the Social: Personal Troubles and Public Issues

The last few decades have seen the rise of a culture of hyper-individualism in the UK, USA and elsewhere, reversing a tentative trend towards greater social cohesion and solidarity that began to emerge in the first half of the 20<sup>th</sup> century. The current scenario has largely been driven by a political and public discourse stressing that autonomous individuals and their families are solely responsible for their own destinies, life chances, fortunes and misfortunes, on an equal footing with their 'competitors', a standpoint that contrasts starkly with C. Wright Mills' famous aphorism that '(N)either the life of an individual nor the history of a society can be understood without understanding both'.

Denigration of the role of the social and structural organisation in governing everyday lives and life chances has also been accompanied by a long sequence of public policy 'reforms', that seem tailored to increasingly favour individual greed, selfishness, discrimination and division over collective need, solidarity and empathy. Moreover, these developments have also been accompanied by the stigmatisation of various group defined as 'other', reducing public sympathy for those least fortunate who have lost out in the Social Darwinist competition this credo has inspired. Amongst a range of regressive developments, this has supported the dismantling of social supports that were once considered essential to both individual security and social progress.

The broad theme of our 2017 conference will consider how we might explore and challenge misrepresentations of the relationship between the personal and the public realm, while focusing upon the myriad ways in which social arrangements govern our lives, including the various ways in which inequitable social arrangements constrain the life chances of the marginalised, in terms of class, race, ethnicity, disability and gender. We are interested in papers that speak to the personal as well as the public, and those that link both.

Suggestions for grouped sessions within all streams are welcomed. All BSA Study Groups are encouraged to contribute posters/papers and other activities. There will also be an opportunity for study groups to meet independently.

#### Online Abstract Submission

<http://www.britsoc.co.uk/events/bsa-annual-conference/submissions.aspx>

#### Important Dates

Friday 14 October 2016

Abstract submission deadline

Friday 13 January 2017

Presenter booking deadline

#### Contact the BSA Events Team

Email: [events@britsoc.org.uk](mailto:events@britsoc.org.uk)

Telephone: +44 (0)191 383 0839



# The British Sociological Association Medical Sociology 48<sup>th</sup> Annual Conference

Aston University, Birmingham  
Wednesday 7 - Friday 9 September 2016

## Conference Programme and Abstract Book

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# Welcome

## BSA Medical Sociology Group 48<sup>th</sup> Annual Conference

Welcome to the 48<sup>th</sup> Annual Conference of the BSA Medical Sociology Group. We are particularly pleased to welcome our plenary speakers, Professor Nick Watson, University of Glasgow, who will give the opening plenary, entitled '**Making the Links, Disability Studies and Medical Sociology**' and Professor Davina Allen of Cardiff University, who will close the Conference with her plenary, '**Object Lessons from the Boundaries of Healthcare**'. We also extend a warm welcome to our international delegates and those attending the conference for the first time.

All delegates are invited to attend the poster presentation and SHI Drinks Reception, kindly sponsored by Wiley, in Litchfield Lounge, CAMS on Wednesday evening at 18:00. This is always a good opportunity to meet new people at an early stage in the conference. The **2016 Conference drinks reception and dinner**, will take place on Thursday 8 September in the Dining Rooms, Courtyard Restaurant followed by a DJ and Disco. Precise times and locations for these and other events can be found in the Delegate Information part and on the Conference Timetable.

The **Annual General Meeting of the BSA Medical Sociology Group** will take place on Thursday 8 September during lunchtime in Room 145, First Floor, Conference Aston Building. All are welcome to this meeting, which is an important opportunity to discuss the future shape of the Conference and other initiatives within the medical sociology community. We would particularly like to invite people to attend who have not done so before. At the meeting, we will be appointing one new Postgraduate Research Student (PGRS) member and an ordinary member of the committee, and we are keen to hear from people who are interested in being considered. Please contact any MedSoc Committee member for more details about either role. All of the committee details are listed on page 10. To view the minutes from the 2015 AGM, see page 117.

We are also delighted to announce a number of special academic events and sessions over the three days of the Conference: there is a **MedSoc Committee Event titled 'Cost of Living'** this year kindly hosted by Ted Schrecker of Durham University, and symposia on '**Environment and Health: Sociological Intersections**', '**Transforming Health Care: Theoretical and Methodological Perspectives on Major Service Change**', and '**The Crisis of Emergency Health Care in South Coast England**'. There are more special events and symposia at the conference, please see page 22 for more details. We are delighted to continue with the popular '**Pecha Kucha**' presentation format with each presentation lasting 6 minutes and 40 seconds.

A dedicated **session for poster presentations** will continue in 2016, and we will award one prize of £100 book vouchers, generously donated by SAGE – the prize is for the best poster as judged by conference delegates. There will be a combined drinks reception and poster viewing session kindly hosted by the *Sociology of Health and Illness* Journal. For more details please go to page 34. **Please don't forget to vote for the best poster!** Voting slips can be found at the registration desk and the ballot box will be near the posters. The winner will be announced at the Conference dinner, along with the winner of the Foundation for the Sociology of Health and Illness (FSHI) 2016 book prize.

We would like to thank everyone who is presenting work, chairing a session or contributing in some way to the organisation of this event. We welcome any comments or suggestions you may have on the format or organisation of the conference. Let us know your views by attending the AGM or by completing the online evaluation after the event. We hope that you enjoy all aspects of the conference.

# Delegate Information

The BSA Medical Sociology Group Annual Conference 2016 is being hosted by Aston University, Birmingham. Conference registration, sessions and exhibition space can be found on the Aston University campus in CAMS (Conference Aston Meeting Suites), Main Building, Aston University, Aston St, Birmingham, West Midlands, B4 7ET.

## REGISTRATION/HELP DESK

BSA staff along with the Medical Sociology Study Group committee members will be available in the Litchfield Lounge, CAMS to register delegates at the following times:

Wednesday 7 September	10:30 - 17:00
Thursday 8 September	08:30 - 17:00
Friday 9 September	08:30 - 12:00

At registration you will be given your conference pack, including the Conference Programme & Abstract Book along with your conference badge.

**During the Conference your conference badge must be worn at all times for security reasons and meal provision.**

Staff will be available in the Litchfield Lounge, CAMS ready to answer any delegate queries.

## ACCOMMODATION

If you have booked your accommodation during the booking process you can collect your keys from the Conference Aston desk in CAMS for campus and hotel accommodation. Check in is 2pm and check out is 11am for both types of accommodation. Please note that there is a penalty for keys not returned for campus accommodation at the charge of £35.00 per key.

The Reception at Conference Aston located within Aston Business School is open 24 hours. If you have a query during your stay and are staying at the hotel or within campus accommodation and you require assistance please contact the reception team on 0121 204 3011.

## CONTACT AT THE CONFERENCE

There will be a message board situated near the registration desk where delegates can leave messages for each other.

Alternatively, urgent messages can be left by telephone to the BSA Events mobile phone: [+44] (0)7825 157 068. These messages will be displayed on the conference message board.

## LOCAL INFORMATION

### Transport to and from the Venue

Taxis should be available to make the short trip between any of the three Birmingham train stations and the Conference venue. Please note these may be busy on Friday afternoon. Therefore please book in advance if you need to make a specific train.

Conference Aston are able to offer onsite car parking facilities. Please visit the website to pre book and pay for your car parking arrangements before you arrive: <http://www.conferenceaston.co.uk> - <http://www.conferenceaston.co.uk/carparking>. Conference Aston also recommends parking at Millennium Point which is a Pay and Display and a short walk from the hotel.

If you wish to walk from the Conference to the stations, Conference Aston has developed interactive Google walking maps, from New Street and Snow Hill train stations, available for download from [www.conferenceaston.co.uk](http://www.conferenceaston.co.uk)

If you wish to travel by public transport to any of the three Birmingham train stations please take any of the coach numbers listed below, in any direction. A large number of National Express West Midlands coaches stop at Corporation Street in the city centre which is only a very short walk from Aston University. Alternatively, you can take coaches which stop at the following roads which are also very close to the University.

Lancaster Circus:	
65	905
67	914
902	915
Jennens Road:	
14	72
55	94
James Watt Queensway:	
33	934
51	935
907	952

### CONFERENCE MEALS AND REFRESHMENTS

#### Tea and Coffee

Refreshments will be served in Litchfield Lounge in CAMS, Main Building throughout the Conference.

Wednesday 6 April	10:30 - 17:00
Thursday 7 April	08:30 - 17:00
Friday 8 April	08:30 - 13:30

#### Lunch

Your Conference badge must be worn at all times for security reasons and for meal provision. All registered delegates can collect lunch from the food points in the Courtyard Restaurant, Conference Centre. To avoid queues delegates are encouraged to make use of the full range of meal times:

Wednesday 6 April	11:30 - 12:45
Thursday 7 April	12:00 - 14:00
Friday 8 April	13:30 - 14:30

#### SHI Drinks Reception

*Sociology of Health and Illness* and Wiley are the kind sponsors of the drinks reception on Wednesday, 7 September at 18:00 in Litchfield Lounge, CAMS. We would like to thank them and we welcome everyone to attend.

## WILEY

#### Conference Dinner and Drinks

The 2016 Conference Dinner will take place in the Dining Rooms, Courtyard Restaurant, and Conference Aston Building on Thursday 8 September at 19:30. We will start the evening with a Drinks Reception in the Courtyard Lounges, Conference Aston Building at 19:00. The Foundation for the Sociology of Health and Illness Book Prize and the Poster Prize will be awarded at the Conference Dinner.

#### Special Dietary Requirements

Special dietary requirements, vegetarian and vegan meals have been pre-booked as per your booking form. If you have requested a special diet, please inform the catering staff when you collect your meals.

#### Breakfast & Evening Meals

Breakfast and evening meal on Wednesday, 7 September will be provided for all delegates who have booked through the BSA booking process for either campus or hotel accommodation in the Courtyard Restaurant, Conference Aston Building.

There are a variety of options for evening meals in Birmingham. There are a number of bars and restaurants not far from the university.

## Delegate Information

### PLACES TO EAT

Restaurant	Address	Website
Pizza Express	Level 7 & 9, Bullring Shopping Centre, Birmingham, West Midlands B5 4BU 15 mins walk	<a href="https://www.pizzaexpress.com">https://www.pizzaexpress.com</a>
Marco Pierre White at Hotel La Tour	Hotel La Tour, Albert Street, Birmingham, United Kingdom B5 5JE, United Kingdom 10 mins walk	<a href="http://www.mpwrestaurants.co.uk/restaurants/chophouse-birmingham">http://www.mpwrestaurants.co.uk/restaurants/chophouse-birmingham</a>
San Carlo	Birmingham, 4 Temple Street, Birmingham B2 5BN, United Kingdom 15 mins walk	<a href="http://www.sancarलो.co.uk/birmingham">http://www.sancarलो.co.uk/birmingham</a>
Bodega	Bodega Bar & Cantina, 12 Bennett's Hill, Birmingham B2 5RS, United Kingdom 15 min walk	<a href="http://www.bodegacantina.co.uk/locations/birmingham/">http://www.bodegacantina.co.uk/locations/birmingham/</a>
The Botanist	The Botanist, 14-16 Temple Street, Birmingham B2 5BG, United Kingdom 15 mins walk	<a href="http://thebotanist.uk.com/location/birmingham">http://thebotanist.uk.com/location/birmingham</a>
Buffalo & Rye	11 Bennett's Hill, Birmingham B2, United Kingdom 15 mins walk	<a href="http://www.buffaloandrye.co.uk/">http://www.buffaloandrye.co.uk/</a>
Chung Ying Central	126 Colmore Row, Birmingham B3 3AP, United Kingdom 15 mins walk	<a href="http://www.chungyingcentral.co.uk/">http://www.chungyingcentral.co.uk/</a>
The Cosy Club	Bennett's Hill, Birmingham B2 5RE, United Kingdom 15 mins walk	<a href="http://www.cosyclub.co.uk/birmingham">http://www.cosyclub.co.uk/birmingham</a>
The Lost & Found	8 Bennett's Hill, Birmingham B2 5RS, United Kingdom 15 mins walk	<a href="http://the-lostandfound.co.uk/">http://the-lostandfound.co.uk/</a>
The Bureau	The Bureau Bar Birmingham, 110 Colmore Row, Birmingham, West Midlands B3 3AG, United Kingdom 15 mins walk	<a href="http://www.thebureaubar.co.uk/">http://www.thebureaubar.co.uk/</a>
Utopia	Utopia the Country Bar, 16 Church Street, Birmingham B3 2NP, United Kingdom 15 mins walk	<a href="http://www.bar-utopia.co.uk/">http://www.bar-utopia.co.uk/</a>

### LUGGAGE STORAGE

During the conference, free-of-charge luggage storage is provided in Room 161, First Floor, Main Building. The opening times are as follows:

Wednesday 7 September	10:30 - 18:30
Thursday 8 September	08:30 - 18:30
Friday 9 September	08:30 - 14:00

### INTERNET ACCESS

#### Wireless Internet Connection

Wireless internet is available across the university campus, enabling delegates to use their own laptops to connect to the internet. Please see the following page for details of how to log in.

**Please use your own laptop if you wish to use this facility, as neither the venue nor the BSA will provide laptops or computers.**

#### eduroam

Aston University is an **eduroam**-enabled institution. **eduroam** is the roaming infrastructure used by the international research and education community. Being part of **eduroam** allows users to access a wireless network at a host institution who is also connected to **eduroam** using the same credentials (i.e. username and password) the users would use if they were at their home institution. As an end-user, you will only be able to use **eduroam** if your institution provides an electronic identity (e.g. account for network access). If you have not been provided with this information, you will need to contact your home university administrator and ask for an account. You (or your network administrator) will have to configure your computer to enable **eduroam** access.

### ANNUAL GENERAL MEETING

The BSA Medical Sociology Group Annual General Meeting will take place on Thursday 8 September in Room 145, First Floor, Conference Aston Building. The meeting will begin at 12:45 and is planned to be finished by 13:45. All delegates are welcome but only BSA Members are eligible to vote.

### CHAIRING

We are extremely grateful to all those who have agreed to chair a session at the Conference. If you have agreed to chair but are not able to make the session for any reason, please let us know at the registration desk so we can find an alternative. If you find yourself in a session without a chair, we'd be very grateful if someone in the audience could volunteer to watch the time and if necessary field questions to allow the presenters to focus on their papers.

### MENTORING

Several conference delegates have kindly volunteered to share their knowledge and skills as mentors and a limited number of slots will be allocated each day on a first-come-first-served basis to facilitate this. Please visit the registration desk for more information.

### PECHA KUCHA

This year a number of 'work-in-progress' papers have been offered to present in a new format, known as Pecha Kucha. Originating from Japan, Pecha Kucha is a shorter form of presentation consisting of 20 slides / images each timed to show for 20 seconds (making a total presentation time of 6 minutes 40 seconds). Pecha Kucha presentations tend to be very engaging and create an upbeat, high-energy atmosphere for both presenters and audiences. There are 2 Pecha Kucha presentations at this year's conference in Steelhouse 3, CAMS meeting rooms starting at 09:00 on Friday 9 September.

### POSTERS

Posters can be viewed in the Litchfield Lounge, CAMS, Main Building. Presenters will be available alongside their posters on Wednesday 7 September from 18:00 to 19:00, along with a drinks reception kindly hosted by *the Sociology of Health and Illness Journal*.

Please don't forget to vote for the best poster. Voting slips can be found at the registration desk and the ballot box will be near the posters. Voting will close at 18:00 on Thursday 8 September, and the winning poster will be announced at the Conference dinner, along with the winner of the 2016 Foundation for the Sociology of Health and Illness Book Prize.

## Delegate Information

### **PUBLISHERS AND EXHIBITORS**

We would like to warmly thank our sponsors and exhibitors for their continued support at BSA conferences and events. The following organisations have sponsored the 2016 Medical Sociology Conference:

Foundation of Sociology of Health and Illness

John Wiley and Sons

Palgrave MacMillan

SAGE

Taylor & Francis/Routledge

### **Pecha Kucha**

Look out for the Pecha Kucha presentations on Friday 9 September at 9:00 in Steelhouse 3, CAMS.

Pecha Kucha is an upbeat and lively Japanese presentation format.

- Each presentation has exactly 20 slides
- Each slide lasts for exactly 20 seconds
- Slides advance automatically
- Total presentation time 6 minutes 40 seconds
- Concise, engaging and pacey

# BSA Medical Sociology Group Committee 2015/2016

Anika Baddeley	BSA Sociologists Outside Academia	Access Requirements / Special Needs / Audio Visual / Social Programme / FSHI Book Prize
Paul Bissell	University of Sheffield	Access Requirements / Audio Visual
Donna Bramwell	University of Manchester	FSHI Book Prize
Flis Henwood	University of Brighton	Programme Committee
Sarah Hoare	University of Cambridge	Postgraduate Representative
Jen Remnant	Newcastle University	Postgraduate Representative
Sasha Scambler	King's College London	Communications / Blog / Programme Committee
Ewen Speed	University of Essex	Co-Convenor / Blog / MSo / Communications / Regional Groups
Sharon Spooner	University of Manchester	Mentoring@MedSoc
Fiona Stevenson	University College London	Co-Convenor / Regional Groups
Lynne Stobbart	Newcastle University	FSHI Book Prize
Paul Whybrow	University of Bristol	Social Programme

## OTHER COMMITTEE MEMBERS

### Ex Officio representation on committee for BSA Council as Medical Sociology Group Liaison:

Sally Brown, Edinburgh Napier University (2015 - 2016), Julia Hiscock, Bangor University (2015 - 2016)

\*\*\*\*\*

**Sociology of Health & Illness Editorial Team:** Davina Allen, Eva Elliott, David Hughes, Joanna Latimer, Ian Rees Jones and Gareth Williams

\*\*\*\*\*

**BSA Office:** Liz Brown, Joan Carr, Sandria Charalambous, Kerry Collins, Alison Danforth, Elaine Forester, Sophie Jaques, Margaret Luke, Gillian Mason, Judith Mudd, Gillian Rae, Claire Simmons, Tony Trueman and Donna Willis

\*\*\*\*\*

## ACKNOWLEDGEMENTS

As always many people have helped with organising the Conference. The Committee would like to extend their thanks for this support.

# Conference Timetable

## What's Happening When

### Wednesday 7 September 2016

10:30 - 17:00	Registration	CAMS, Main Building
10:30 - 17:00	Tea & Coffee	Litchfield Lounge, CAMS, Main Building
11:30 - 12:45	Lunch	Courtyard Restaurant, Conference Aston Building
12:45 - 16:45	Paper Sessions	Main Building
13:55 - 15:35	Special Event: Health Capital	Whitehall 3, CAMS
17:00 - 18:00	Opening Plenary	Great Hall, Main Building
18:00 - 19:00	Poster Presentation and SHI Drinks Reception	Litchfield Lounge, CAMS, Main Building
19:00 onwards	Dinner on campus	Courtyard Restaurant, Conference Aston Building

### Thursday 8 September 2016

07:00 - 09:00	Breakfast	Courtyard Restaurant, Conference Aston Building
08:30 - 17:00	Registration	CAMS, Main Building
08:30 - 17:00	Tea & Coffee	Litchfield Lounge, CAMS, Main Building
09:00 - 12:25	Paper Sessions	Main Building
09:00 - 10:40	Special Event: Environment and Health	Steelhouse 2, CAMS
10:45 - 12:25	Special Event: Transforming HC	Steelhouse 2, CAMS
12:00 - 14:00	Lunch	Courtyard Restaurant, Conference Aston Building
12:45 - 13:45	BSA Medical Sociology Group AGM	Room 145, First Floor, Conference Aston Building
14:00 - 18:00	Paper Sessions	Main Building
14:00 - 15:40	Special Event: Emergency HC	Steelhouse 3, CAMS
14:00 - 15:40	Special Event: Autistic Assemblages	Byng Kendrick, G11, Main Building
16:20 - 18:00	Special Event: Cost of Living Blog	G63, Main Building
16:20 - 18:00	Special Event: Parent Drug Use	Steelhouse 2, CAMS
16:20 - 18:00	MedSoc Committee Event	Whitehall 2, CAMS
19:00 - 19:30	Drinks Reception	Courtyard Lounges, Conference Aston Building
19:30 - 00:00	Conference Dinner	Dining Rooms, Courtyard Restaurant, Conference Aston Building

### Friday 9 September 2016

07:00 - 09:00	Breakfast	Courtyard Restaurant, Conference Aston Building
08:30 - 12:00	Registration	CAMS, Main Building
08:30 - 13:30	Tea & Coffee	Litchfield Lounge, CAMS, Main Building
09:00 - 12:25	Paper Sessions	Main Building
09:00 - 10:40	Special Event: Understanding Social Inequalities in Health	Stafford 1, CAMS
09:00 - 10:05	Pecha Kucha	Steelhouse 3, CAMS, Main Building
12:30 - 13:30	Closing Plenary	Great Hall, Main Building
13:30 - 14:30	Lunch and End of Conference	Courtyard Restaurant, Conference Aston Building

# Programme Grid 2016

(Programme arranged by stream)

## Wednesday Afternoon – 7 September 2016

Registration opens from 10:30 in CAMS

11:30 - 12:45 Refreshments and Lunch (Courtyard Restaurant, Conference Aston Building)

MAIN BUILDING									
Stream	Critical Public Health (2), Theory (4)	Ethnicity (2) Inequalities (3)	Experiences of Health and Illness	Health Service Delivery	Lifecourse	Mental Health	Politics of Health	Professions	STS and Medicine
Room	Whitehall 2 CAMS	Whitehall 3 CAMS	G63	Stafford 2 CAMS	Steelhouse 2 CAMS	Whitehall 1 CAMS	Steelhouse 3 CAMS	Stafford 1 CAMS	Byng Kendrick G11
12:45 - 13:15	Kirk, L.	Atcha, M.	Hillman, A.	Chng, N. R.	Bonnar, K.	Pratt-Boyden, K.	Røberg, A.	Mahendran, A.	Swallow, J.
13:20 - 13:50	Wyke, S.	Mantovani, N.	Bellass, S.	Hardicre, N.	Hoare, S.	Spence, C.	Lin, Y-L	Belle, M-J	Corbett, K.
13:55 - 14:25	Waring, J.	SPECIAL EVENT: Health Capital Larsen, K. et al	Rees, S.	Goodwin, R.	Hudson, N.	Markham, S.	Hilton, S.	Moth, R	Sanchez-Vazquez, A.
14:30 - 15:00	Yuill, C.		Neal, K.	Cummins, C.	Fitzgerald, L.	Moth, R.	Chekar, C. K.	Brosnan, C.	Atkinson, S.
15:05 - 15:35	Olsvsold, N.		Makela, P.	Mathieson, A.	Cheshire, A.	Shepherd, A.	Dimond, R.	Marrable, T.	Milne, R.
15.40 - 16.10	Marent, B.	Kriznik, N.	Brewis, C.	Melby, L.	Kirkpatrick, S.	Brown, G.		Højbjerg, K.	Overton, C.
16:15 - 16:45		Sointu, E.		Hope, J.	Shah, S.	Steggals, P.			Jeffries, M.

17:00 - 18:00 Opening Plenary: Professor Nick Watson (Great Hall, Main Building)

18:00 - 19:00 Poster Presentation and SHI Drinks Reception (Litchfield Lounge, CAMS, Main Building)

**Thursday Morning – 8 September 2016**

07:00 - 09:00 Breakfast (Courtyard Restaurant, Conference Aston Building)

<b>MAIN BUILDING</b>									
<b>Stream</b>	<b>Citizenship and Health</b>	<b>Environment and Health</b>	<b>Experiences of Health and Illness</b>	<b>Health Care Organisations (3) &amp; Health Policy (3)</b>	<b>Methods</b>	<b>Patient Professional Interaction (5) &amp; Open (1)</b>	<b>Pharmaceuticals (4)</b>	<b>Screening and diagnosis (4)</b>	<b>STS and Medicine (3) &amp; Gender (3)</b>
<b>Room</b>	<b>Stafford 1 CAMS</b>	<b>Steelhouse 2 CAMS</b>	<b>G63</b>	<b>Stafford 2 CAMS</b>	<b>Whitehall 1 CAMS</b>	<b>Whitehall 3 CAMS</b>	<b>Steelhouse 3 CAMS</b>	<b>Whitehall 2 CAMS</b>	<b>Byng Kendrick G11</b>
09.00 - 09.30	Hiscock, J.	SPECIAL EVENT: Environment and Health Fox, N.		Farre, A.	Sheard, L.	Ziebland, S.		Moen, H.B.	Broer, T.
09:35 - 10:05	Parsons, J.		Polak, L.	Sanders, T.	Yiallourous, J.	Woods, C.	Abraham, J.	MacArtney, J.	Stelmach, A.
10:10 - 10:40	Bonyeme, L.		Walker, L.	Nordin, P.	Mwale, S.	Rasmussen, E.	Lloyd, K.	Solbjør, M.	Lewis, J.
10:45 - 11:15	Nikolov, P.	SPECIAL EVENT: Transforming HC Jones, L. et al	Møller Hansen, U.	Checkland, K.	Grant, A.	Hughes, S.	Montgomery, C.	Mutch, A.	Gilman, L.
11:20 - 11:50	Green, J.		Black, R.	Håland, E.	Pilnick, A.	Franklin, M.	Cooper, R.		Idris, D.
11:55 - 12:25			Patterson, R.	Wilson, N.	Grant, S.	Feiring, M.			Castro-Vazquez, G.

12:00 - 14:00 Lunch (Courtyard Restaurant, Conference Aston Building)

12:45 - 13:45 BSA Medical Sociology Group Annual General Meeting (Room 145, First Floor, Conference Aston Building)

Thursday Afternoon – 8 September 2016

MAIN BUILDING									
Stream	Ethics	Experiences of Health and Illness	Health Service Delivery (1) & Health Care Organisations (1)	Lifecourse (2) & Critical Public Health (1)	Mental Health	Methods (1) & Citizenship and Health (2)	Patient Professional Interaction	Risk (3)	STS and Medicine
Room	Whitehall 1 CAMS	G63	Steelhouse 3 CAMS	Steelhouse 2 CAMS	Stafford 2 CAMS	Stafford 1 CAMS	Whitehall 3 CAMS	Whitehall 2 CAMS	Byng Kendrick G11
14:00 - 14:30	Job, K.	Winance, M.	SPECIAL EVENT: Emergency HC Bendelow, G. et al	McCormack, F.	Cant, S.	Grant, A.	Rondelez, E.	Pack, R.	SPECIAL EVENT: Autistic Assemblages Fitzgerald, D. et al
14:35 - 15:05	Ri, I.	Cramer, H.			Jacobi, C.		Lindenmeyer, A.	Cunningham, Y.	
15:10 - 15:40	Street, H.	Heavey, E.		Pack, R.		Tritter, J.	Corrigan, O.	Brown, S.	
15:45 - 16:15	Doyle, E.	Isaacs, A.	Martin, G.		Werner, A.	Maguire, K.	Loughran, I.		Strange, H.
16:20 - 16:50	Sukumar, P.	SPECIAL EVENT: Cost of Living Blog Schrecker, T.		SPECIAL EVENT: Parent drug use Chandler, A. et al			Eccles, A.	MedSoc Committee Event Stevenson, F.	Cunningham-Burley, S.
16:55 - 17:25									Faulkner, A.
17:30 - 18:00									

19:00 Drinks Reception (Courtyard Lounges, Conference Aston Building) and Conference Dinner (Dining Rooms, Courtyard Restaurant, Conference Aston Building)

**Friday Morning – 9 September 2016**

07:00 - 09:00 Breakfast (Courtyard Restaurant, Conference Aston Building)

<b>MAIN BUILDING</b>									
<b>Stream</b>	<b>Critical Public Health</b>	<b>Experiences of Health and Illness</b>	<b>Health Policy</b>	<b>Health Service Delivery (4) &amp; Citizenship (1)</b>	<b>Inequalities (1) &amp; Lifecourse (3)</b>	<b>Patient Professional Interaction (2) Methods (3)</b>	<b>Pecha Kucha (2) &amp; CAM* (2) &amp; Embodiment (2)</b>	<b>STS and Medicine</b>	<b>Teaching (1) &amp; Open (2)</b>
<b>Room</b>	<b>Steelhouse 2 CAMS</b>	<b>G63</b>	<b>White Hall 1 CAMS</b>	<b>Stafford 2 CAMS</b>	<b>Stafford 1 CAMS</b>	<b>White Hall 3 CAMS</b>	<b>Steelhouse 3 CAMS</b>	<b>Byng Kendrick G11</b>	<b>White Hall 2 CAMS</b>
09.00 - 09.30	Bissell, P.	Grant, A.	Georgiadis, A.		SPECIAL EVENT: Understanding Social Inequalities in Health Hindhede, A. et al	Hinton, L.	PECHA KUCHA: Walmsley, I. Eccles, A.	Fletcher, I.	Dikomitis, L.
09:35 - 10:05	Noonann-Gunning, S.	Jamie, K.	Lavery, L.	Dowrick, A.		Foley, G.		Gonzalez Aguado, M.	Maddison, J.
10:10 - 10:40	Bissell, P.	McNiven, A.	Williams, O.	Underwood, J.			Lytovka, M.	Nino, N.	Van Den Bogaert, S.
10:45 - 11:15	Blackburn, M.	Griffith, V.	Lynch, A.	Rae, R.	Roberts, J.	Tjora, A.	Krouwel, M.	Saukko, P.	
11:20 - 11:50	Larsen, J.A.		Hedlund, M.	Godfrey, M.	Baldwin, K.	Cheung, O.	Karasaki, M.	Pickersgill, M.	
11:55 - 12:25	Dumbili, E.		Hutchison, J.	Mahon-Daly, P.	Amakor, G.	Lempp, H.	Clarke, J.		

12:30 - 13:30 Closing Plenary: Professor Davina Allen (Great Hall, Main Building)

13:30 - 14:30 Lunch (Courtyard Restaurant, Conference Aston Building)

\*CAM - Complementary and Alternative Medicines





# Opening Plenary

Wednesday 7 September 2016 at 17:00 - 18:00  
Great Hall, Main Building

## Professor Nick Watson

### **MAKING THE LINKS: DISABILITY STUDIES AND MEDICAL SOCIOLOGY**

2016 marks the 40th anniversary of the publication of the *Fundamentals of Disability* by the Union of the Physically Impaired Against Segregation. This document sought to politicise disability and developed an alternative perspective to define the social problems faced by disabled people, their origins and their solution. It argued that disability should not be explored at the individual level with a focus on the way that impairments constrain disabled people's lives but rather should explore the disadvantage experienced by disabled people arising as a result of social, cultural and economic discrimination. Importantly UPIA's statement was directed not just at disabled people but at those who researched disability, arguing that emphasis should be on structural rather than individual change.

By laying the roots of what was to become the social model of disability, *Fundamental Principles* played a crucial part in the establishment of disability studies and to the consequent parting of the ways between these "organic intellectual" theorists of disability and academics within the field of medical sociology. Since the early 1990s disability studies and medical sociology have largely gone our own separate ways, albeit with one or two exceptions and this has been to the detriment of both disciplines resulting in the production of incomplete explanations.

In this paper I will draw on a broad spectrum of research including work with disabled children, people with motor neurone disease, the provision of health and social care, the history of the wheelchair and learning from What Works Scotland to try and create links between disability theory and medical sociology. Adopting a critical realist approach and drawing on the work of Nancy Fraser and Martha Nussbaum, this presentation will argue that medical sociology and disability studies must work together if we are to effectively create research that not only documents the lives of disabled people but also presents political strategies for improving the lives of disabled people. The need for this convergence is becoming even greater as the impacts of austerity start to roll out across the Global North.





# Closing Plenary

Friday 9 September 2016 at 12:30 - 13:30  
Great Hall, Main Building

## Professor Davina Allen

### OBJECT LESSONS FROM THE BOUNDARIES OF HEALTHCARE

Because of its complexity healthcare has long provided a natural laboratory for the study of work. Yet while a source of endless fascination for medical and organisational sociologists, for clinicians and service managers the practical challenges of dealing with this complexity and the consequences of getting it wrong have increasingly come to the fore.

The last 30 years has witnessed an explosion of interventions intended to ensure the quality and safety of health services. Informed by systems engineering and management science, numerous technologies have been imported into the sector from fields such as aviation or manufacturing, in the interests of quality improvement. In my presentation I want to reverse this flow of ideas and consider what lessons other organisational settings might learn from healthcare.

My starting point is a recently completed ethnographic study designed to shine a light on the invisible 'organising work' of hospital nurses. Nurses, it is argued, operate as 'obligatory passage points' in contemporary health systems, deploying 'translational mobilisation' practices to funnel, refract and shape care delivery. This work is not system-fixing as some would have it, but a necessary counterbalance to the inherent flux, instability and uncertainty of everyday healthcare delivery.

Hospitals are prima facie examples of complex, turbulent and fluid environments, but this characterisation applies to many organisations in late modernity where knowledge-sharing is emergent and the objects of practice unstable. I plan to elaborate on the ideas developed in my observations of nursing work and introduce a formal theory of translational mobilisation as a framework that will enable these practices to be systematically examined wherever they are found. This is a necessary to advance understanding of organisational processes not only in healthcare but a range of institutional contexts, and also to rebalance organisational learning across sectors.





# Symposia and Special Events

**Wednesday 07 September 2016 at 13:55 - 15:35**

## **Inequalities**

**WHITEHALL 3, CAMS**

### **Health Capital. A Bourdieu Inspired Study of Social Differentiated and Differentiating Investments in the Body**

*Larsen, K., Harsløf, I.*

*(Department of Education, Learning and Philosophy, Aalborg University, Copenhagen)*

This paper discusses the emergence of health as an object of personal investment in the post-industrial society and its implications for social inequalities in health. Expanding on Pierre Bourdieu's theory of the forms of capital, it proposes the notion of health capital as a theoretical construct, encompassing embodied, objectified and institutionalized health assets.

We focus on individual and group investment in the body, from conspicuous nutrition strategies and forms of exercise to plastic surgery). We argue that such investments are socially differentiated and differentiating. Dominant groups define the 'healthy game' and habitually they know what is the distinctive, what is desirable and what is vulgar.

Possessing health capital gives access to privileges at a wide range of fields across the sphere of production (labour market) and social reproduction (family/civil society). Hence, we regard the accumulation of health capital as a crucial strategy of reproducing social positions among dominant groups.

While this contribution is mainly theoretical, as an initial exploration, we analyze own empirical data from interview studies and European Social Survey (ESS) Round 7 (2014). Adopting Esping-Andersen's (1993) post-industrial class classification scheme, the paper explores patterns of health investments among high and low positioned groups in the social structure – in welfare states representing different stages of post-industrial development. The ESS data allow us to index health assets (body mass, nutrition, alcohol/tobacco consumption, physical exercise, consumption of alternative medicine) in order to tap into the theoretical construct of health capital.

**Thursday 08 September 2016 at 09:00 - 10:40**

## **Environment**

**STEELHOUSE 2, CAMS**

### **Environment and Health: Sociological Intersections**

*Fox, N.*

*(University of Sheffield)*

A growing body of research and theory on the interactions between the environment and human health indicate the need for sociological perspectives that can explicate these. The aim of this symposium, which is organised by the Environment and Health Special Interest Group, is to bring together papers that explore in different ways how sociological theory, empirical social inquiry and policy analysis can supply insights into health/environment intersections. This will build upon a successful day conference organised in conjunction with the BSA Climate Change Study Group in February 2016 that reported a broad range of empirical studies around environment and health.

The format of the symposium will be three 20-minute papers, followed by half an hour of open discussion. The extended opportunities for analysis that this format affords will enable a wide range of issues to be addressed, including:

1. The intersections between environment, health, and other social variables including gender and lifestyle.
2. How sociological theory can inform and address conflicts and congruities between human health and the natural environment.
3. How sociologists of health and the environment can engage with pressing public concerns, through research, policy initiatives and activism.
4. Sociological futures around environment, health research and policy.

Chair: Richard Compton (King's College, London)

## Symposia and Special Events

### **Sustainability as Ecological Potential: Environment, Sociology and the Posthuman**

*Fox, N.*  
(University of Sheffield)

This paper re-thinks environmental sustainability as the maximisation of ecological potential. I argue for a posthuman sociology of environment and health that counters forces that constrain the environment's potentialities and fosters instead those that enhance environmental (and in the process, human) potentiality. The first part of the paper develops this thesis through the example of an initiative by public health staff in a city council to improve health by reducing the number of vehicles using the roads during peak times, thus cutting pollution and road traffic accidents, and encouraging people to walk more or use bicycles. I explore this problem via 'new materialist' sociology, in terms of the micropolitics of assemblages between human health and the environment. Key to a post-anthropocentric and posthuman perspective is the need to engineer sustainability into the assemblage. However, new materialist ontology poses challenges for notions of environment sustainability, as few assemblages are sustainable, but instead have within them a web of contradictory forces that produce flux and instability. The second part of the paper argues that 'sustainability' needs to be re-thought as environmental potential and becoming.

### **Researching Environmental and Health Behaviours**

*Graham, H., White, P.*  
(University of York)

It is widely recognised that the lifestyles that are seen as responsible for the major burden of ill-health nationally and globally are also ones that are damaging to the environment. However, behaviours with health and with environmental impacts fall within separate research and policy fields, each with its own community, disciplinary base, perspectives, data sets etc. Our paper will explore the scope for integrated approaches, and will introduce a searchable e-resource that holds information on around 40 UK datasets with measures of both environmental and health behaviours. This e-resource has been developed as part of our ESRC HOPE project, with the help of research and policy leads in public health and the environment.

### **The Problem of Realising the Health Benefits of Natural Space for Gender: Contributions to Environment and Human Health from a Sociological Perspective**

*MacBride-Stewart, S.*  
(Cardiff University)

Nature, it is argued, is beneficial for health. The debate about which natural environment is beneficial for health appears inconclusive for gender. The literature suggests that large green rural outdoor spaces and small green urban gardens are positively associated with health, with differences in the meanings and relationships of these spaces with respect to gender. Outdoor public spaces are argued to be particularly intimidating to women. Concepts related to accessibility and use of outdoor space presuppose that women value sociability and design above a preference for individual engagement and exploration, and that this may limit their opportunities to realise the anticipated health benefits of outdoor space. This paper argues that the problem of outdoor rural space for women is not its inaccessibility, but rather our conceptualization of this space in relation to private space. Through two case studies – the first, a conceptual reframing of public, outdoor space and gender via a sociological analysis of family homes and private spaces and the second, a study of geocaching in a National Park - the gender-space-nature-health interconnection is critically reviewed to show how marginalised others might be understood to construct meaningful engagements (even 'healthy ones') in natural environments, in the face of what feminist sociologists have claimed are very real risks to material selves and constituted identities.

**Thursday 08 September 2016 at 10:45 - 12:25**

**Environment**  
**STEELHOUSE 2, CAMS**

### **Transforming Health Care: Theoretical and Methodological Perspectives on Major Service Change**

*Jones, L., Stewart, E., Fraser, A., Waring, J.*  
(University College London)

Large-scale strategic change is an enduring health system reform orthodoxy in high-income countries. It is often the preferred course of action for decision-makers, despite alternatives, and despite limited evidence of either clinical or economic benefits. Major service change has been viewed as a manifestation of managerialism, epitomising

## Symposia and Special Events

standardised, uniform and efficient organisation, and legitimated as originating in the private sector. For politicians and service leaders it serves a 'performative' function, clearly showing that 'something is being done', and yet that same visibility can generate opposition and conflict on the ground.

Much of the research literature assumes that reorganisation is a technical issue, and therefore neglects opposition to strategic change, or views it as one of many factors to be managed. The majority of research is instrumental in focus, orientated to solving the problem of how best to organise health services so as to maximise effectiveness whilst minimising cost. It is also largely normative, in that it presupposes the need for change and is concerned with judging the 'success'. Thus major service change remains both under-socialised and under-theorised. At the same time its complex nature, comprising practices at the macro (system), meso (organisation) and micro (professional) levels, poses considerable methodological challenges for research. This symposium seeks to address this deficit by exploring theoretical approaches, and methodological innovation, in the study of major service change.

### **Conceptualising the Public in Healthcare Transformations: Hospital Closures in the Scottish NHS**

*Stewart, E.*

*(University of Edinburgh)*

Much commentary on major changes to health services assumes that 'the public' is a singular, knowable entity, and an inevitable obstacle to change. Likewise, public campaigns against changes are often keen to present a unified front; defending health services on behalf of 'the public'. Neither acknowledge a more sociological understanding of 'publics' as multiple, shifting and complex.

This paper explores the presence and absence of 'the public' from policy on major service change in the Scottish NHS since devolution. Drawing on interviews and analysis of policy documents I explore the roles ascribed to 'the public' within policy rhetoric around transformation. I then offer some early findings from case studies in the Scottish National Health Service - including campaign groups commissioning independent expert reviews, and attempting community buy-out of threatened facilities – as exemplars of the diversity and sophistication of public action on major service change. From this starting point, we can begin to disaggregate and explore public responses, acknowledging a much wider repertoire of actions beyond protest marches.

### **Studying Major System Change: Methodological Challenges and Opportunities**

*Waring, J.*

*(University of Nottingham)*

'Major system change' raises many sociological questions about the processes of policy formulation and implementation, the structural relationship between care organisations, the flow of patients and resources, and the transformation of local practices, cultures and identities. The types of questions we ask of major system change, and the theories we use to answer them, are concerned with different ontologies of healthcare reform, with each producing distinct methodological challenges associated with determining the different levels and units of analysis. This paper discusses three methodological approaches to the sociological study of major system change, and considers the opportunities and challenges of each. The first develops an interpretative policy analysis, and considers the formulation and implementation of policies as a socially embedded and inherently political process, foregrounding in particular the meaningful actions and interactions of different stakeholders at national and regional levels. The second, draws on methods of system modelling and social network analysis, which are concerned with describing, measuring and mapping the relational ties and interactions between system actors. The third approach might be termed 'multi-site' or 'system' ethnography, which aims to understand the movement of ideas, practices and cultures within and across these structural relationships, including the transformation of epistemic, symbolic and material boundaries. The paper suggests each provides a partial view of major system change, at different ontological levels, and with different opportunities for theorisation. It considers the ways in which these might be combined with a more traditional case-based approach to develop a more holistic viewpoint.

**Thursday 08 September 2016 at 16:20 - 18:00**

**Cost of Living Blog Special Event**

**G63, MAIN BUILDING**

### **'Neoliberal Epidemics' and Health Politics for a New Gilded Age**

*Schrecker, T.*

*(Durham University)*

In 2015, Clare Bambra and I published a book in which we argued that the health consequences of recent economic and social policies in the United States and the United Kingdom are best understood as a set of interacting 'neoliberal

## Symposia and Special Events

epidemics'. Neoliberal epidemics represent an important conceptual advance in understanding health politics in an age in which inequalities are rising and being magnified by public policy. I first review the evidence in support of this proposition, and then explore the underlying political economy and the challenges that it presents for strategies of resistance, focusing on the need to treat public finance as a public health issue; to understand the depth of disparities in the 'epidemiological worlds' that people inhabit; and to think critically about assertions about resource scarcity in an era that combines selective austerity with a systematic upward redistribution of income and wealth. I conclude with some reflections on the politics of evidence and the perils of speaking truth about power: we should be working towards applying a precautionary principle to the health consequences of neoliberal policies, yet researcher careers may increasingly come to depend on acquiescence to elite strategies of 'manufacturing uncertainty' (in David Michaels' words) on this point.

### **Thursday 08 September 2016 at 14:00 - 15:40** **Health Service Delivery** **STEELHOUSE 3, CAMS**

#### **The Crisis of Emergency Health Care in South Coast England**

##### **Police Use of Section 136 of the Mental Health Act as Suicide Prevention Across Sussex**

*Bendelow, G.*  
(University of Brighton)

S136 detentions in Sussex have been under constant governmental and public scrutiny, not only for consistently revealing some of the highest rates in the country (around 1500 pa until 2014) but with two thirds of highly distressed individuals being detained in police custody rather than specialist NHS suites. Using mixed methods, including ethnographic observations, this British Academy/ NIHR funded research project has revealed some of the complexity and has challenged simplistic assumptions. We suggest that the police decision making in emergency mental health situations appears to be an appropriate, risk averse and even compassionate response to extreme emotional distress and has been used mainly for 'out of hours' suicide prevention when no other service is available

##### **The Risky Business of NHS 111**

*Pope, C., Turnbull, J.*  
(University of Southampton)

NHS 111 is a relatively new service providing telephone triage for urgent care. There are concerns that it has increased rather than reduced demand for emergency care services, and this seems to be in part because of the levels of caution and risk that are built into the software that underpins the service. This software has to be sensitive enough to identify patients that need immediate care, not least because the frontline call handling staff are not clinically trained, and can lack specificity, identify false positives and create inappropriate referrals. Our ethnographic case studies of NHS 111 explore risk management in this new context.

##### **An Absence of Trauma**

*Rolfe, U.*  
(University of Southampton)

Contribution from an on-going Phd using ethnographic methods to explore everyday paramedic work. The researcher/student is a paramedic and trainer interested in how paramedics respond to and manage the (increasing) burden of mental ill-health and distress that is presented as 999 (ambulance) calls.

##### **Mental Health Triage and Frequent Callers**

*Warrington, C.*  
(University of Brighton)

This Wellcome Trust funded PhD has a focus on people who regularly contact emergency services when in distress, and the role of the Department of Health funded ten pilot 'Mental Health Triage' schemes rolled out in 2014, which enable police to partner with mental health workers in a direct attempt to reduce the number of mental health detentions to police custody and to provide appropriate support.

### Whatever Happened to Safe Staffing in A&E?

*Recio-Saucedo, A., Pope, C.*  
(University of Southampton)

As social scientists we were part of a larger multidisciplinary team commissioned by NICE to review the evidence of safe nurse staffing in the ED. This was one of a number of systematic reviews of studies of workforce configuration following concerns raised by the Francis Enquiry. An earlier review of safe nurse staffing on general wards had been conducted and national guidance on staffing levels was published and hotly debated. While the review of the evidence for A&E settings was successfully completed the guideline process appeared to go awry at national level.

**Thursday 08 September 2016 at 14:00 - 15:40**

## **STS and Medicine**

**BYNG KENDRICK - G11, MAIN BUILDING**

### **Autistic Assemblages: History, Sociology, Performance**

This special session is concerned with the social study of autism – one of the most pressing, and yet elusive, categories within contemporary biomedicine. Presenting new research from sociology, history, and drama studies, we use a range of theoretical and empirical sources to investigate autism's past and present while focusing on the condition's intersections with a range of medical and scientific disciplines – including epidemiology, molecular genetics, and neuroscience. Across the four empirical papers, we ask: what does a particular focus on autism bring to medical sociology and allied disciplines? What does it mean for medical sociologists to try to bring this object – characterised by social and neurological difference and diversity – into view? What collaborative, methodological, and theoretical innovations might be at stake in such an endeavour?

### **From Deficient to Different: Autism and Dyslexia**

*Campbell, T., Muskett, T.*  
(University of Leeds)

In this paper we wish to explore fragments of the genealogy of autism and dyslexia, two categories now related through the development of the Neurodiversity Movement. Current histories of autism place great significance on the contributions during the 1970s of child psychiatrist Michael Rutter to the development of modern diagnostic frameworks. However, less emphasis has been placed on the intersection between his contemporaneous studies of dyslexia and autism, within which he deployed epidemiological arguments to critique existing contemporary classifications of, and explanatory mechanisms proposed for, these diagnoses. Our examination of Rutter's research during the late 1960s into the 1970s indicates that his concerns about these diagnostic categories were methodologically and theoretically united. In both cases, Rutter repeatedly raises questions couched in the language and practices of epidemiology about the validity of each diagnostic category and the prevailing psychoanalytically-oriented explanations offered to account for them. We will suggest that whilst his proposed shift to the grounding of such diagnoses in behavioural, population-level statistical research had somewhat different implications for each classification, in both cases it ultimately made feasible contemporary understandings of autism and dyslexia as exemplars of 'Neurodiversity' rather than mere psychological 'deficit'. Through these arguments, we explore whether further research should be conducted to understand a possible relationship between the diagnostic diagrams of autism and dyslexia, and the place of each in the others' history.

### **'There's this thing we recognise when we see it and it's this thing called autism' – Neurobiologizing the Autism Spectrum**

*Fitzgerald, D.*  
(Cardiff University)

Within the sociology of psychological and psychiatric diagnosis, there has been a good deal of attention to 'neurobiologization,' viz. the process of locating some otherwise fuzzy categories of human and social life within the bounds of an individual skull. But what does neurobiologization actually look like to a neuroscientist? How does it take place within their practice? And is the process of making a neurobiological account of something as crushingly inevitable, and as crudely reductive, as we sometimes think?

In this paper, I address these questions through a study of the neuroscience of autism. I draw on 30 interviews with researchers trying to find a neurobiological marker for autism, to ask: how do neuroscientists actually think about the labour of trying to neurobiologize something so apparently ungraspable – something as culturally and historically heterogeneous – as the autism spectrum?

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My data shows that, for some researchers, autism is a 'biologically true' neurobiological phenomenon; for others, autism is heterogeneous and separable, a 'symptom check-list' or an 'umbrella of convenience.' But rather than neuroscientists feeling the need to resolve this tension, I will show how the links between autism, societal convenience, and neurobiology, were traced together by thinking about autism through some very different, and quite unexpected, discursive registers. Across this account, I will show that 'neurobiologization' is a more various, complex and uncertain process than we sometimes realize.

### Using Live Art and Performance to Develop Alternative Sensory Methodologies

*Foster, A.*  
(University of Kent)

This paper explores how performance and live art can add to the debate around Autism, especially how it can offer space for people with Autistic Spectrum Condition to communicate their own experiences in ways that aren't always reflected in Neuroscience discourses. Drawing on feminist materialism as a conceptual framework my work addresses a gap in the existing research, through developing interdisciplinary work that engages with neuroscience and live art practice, in order to provide a platform for women to articulate their experience in a way that doesn't privilege language. It details some of my own experiments with visual art (applique and costume design), performance photography and public interventions to convey my experience of "coming out" as an Autistic person. I am currently in the process of developing new methodologies for workshops with other women on the spectrum, in order to carry out practical research into what it looks/feels/smells/tastes/sounds like to be a woman or transgendered person with ASC. I aim to develop visual and performance art collaboratively with participants, to create space and capture sensory experiences that are not captured in verbal communication. In this paper I will present the artwork and pilot workshops I have conducted with a neurodiverse feminist artist collective called G.A.L. Guerilla Art Lab, in Nottingham, which will act as a foundation for the development of these alternative methods.

### What's you AQ? The Quantification of Autism

*Hollin, G.*  
(University of Leeds)

Here I argue that the development of questionnaires assessing the number of 'autistic traits' exhibited by an individual has led to a shift in understandings of autism: Increasingly autism is providing a language through which to understand all humans rather than to demarcate a clinical population. In this talk, and drawing on a wide range of documentary sources, I map the emergence of this novel understanding of autism. I show that these questionnaires – typified by the Autism Quotient or AQ - were developed for studies in molecular genetics: The inability to find genetic markers for autism in the 1990s meant that studies in the new millennium increasingly relied upon the genetic material of parents and other relatives in order to examine 'endophenotypes'; traits below the clinical threshold which could, it was hoped, be mapped onto specific parts of the genome. Once developed, however, these quick and easy to administer questionnaires could also be used to understand the social behaviours of those with no relationship to autism – for example, the loneliness of college students – and, thus, facilitated a striking and novel 'ontology of the self'. This talk, therefore, discusses and historicizes the shifting boundaries between normal and abnormal, present and absent, and deficit and difference in the case of autism and relates these changes to the novel and mundane technologies used in psychology, psychiatry, and genetics.

**Thursday 08 September 2016 at 16:20 - 18:00**

## **Critical Public Health**

**STEELHOUSE 2, CAMS**

### Responses to and Representations of Parents Who Use Drugs: A Cross-Cultural Symposium

#### **Constructing the Causes and Consequences of Neonatal Abstinence Syndrome: Accounts of Parents and Professionals**

*Chandler, A., Whittaker, A.*  
(University of Lincoln)

This paper examines parent and professional accounts of the care and treatment of families whose baby is at risk of Neonatal Abstinence Syndrome (NAS). Participants articulated competing understandings and approaches to the prevention of NAS and the care of mother and baby. NAS itself was constructed in different ways: as an inevitable and relatively unproblematic side-effect of opioid use in pregnancy; as evidence of mismanagement of drug-use among

## Symposia and Special Events

pregnant mothers; as a tragic outcome, irrevocably tied to histories of abuse and neglect. The 'NAS baby' symbolised preventable, yet inescapable, 'risk' (blame) and 'harm' (shame) associated with maternal addiction. Professional accounts framed NAS as a justifiable reason to intervene in the lives of drug-dependent women. Parents reproduced and resisted notions of blame and shame, often with antagonistic accounts of perceived discriminatory treatment. Tensions between professionals and parents, we argue, are an unfortunate and avoidable outcome of current policies in Scotland which frame the 'management' of drug-dependent parents within 'child protection' (not family support) and 'recovery' (not harm reduction) discourses.

### **Governing Families: Representations of Parents Who Use Drugs in Contemporary Irish Drug, Health and Family Policy Documents**

*Devaney, E.*  
(University of Limerick)

Drawing on a Foucauldian-influenced governmentality studies conceptual framework (e.g. Dean 2010, Foucault 2007, Miller and Rose 2008) and using elements of Bacchi's (2009) 'What's the Problem Represented to Be' approach, this paper presents a discourse analysis of contemporary drug, health and children's policy texts in the Republic of Ireland (ROI). Across policy fields there is a discursive silence around parental drug use and pregnancy. Discourse relating to parental drug use is absent in health policy in ROI. In drug and children's policy texts parents who use drugs are constructed as 'risky subjects' who are attributed responsibility for the future life chances of their children; this is framed within a safeguarding discourse. These problematisations legitimise the exercise of disciplinary power and state intervention in the form of surveillance, for example case management interventions such as 'Hidden Harm' protocols, and normalising interventions such as parenting programmes. These individualising forms of governing families overshadow alternative policy solutions such as those that address political and socio-economic conditions that impact on family wellbeing.

### **Canadian Clinical Guidelines for the Provision of Methadone in Pregnancy: Combined and Conflicting Biomedical, Practical and Social Concerns**

*Martin, F. S.*  
(Dalhousie University)

Clinical practice guidelines (CPGs) for the provision of methadone in pregnancy reflect a primarily biological model of addiction, one that portrays successful treatment of opiate addiction in pregnancy as dependent on matters such as effective titration and sufficient monitoring. At the same time, these documents also address extra-medical concerns, such as establishing mechanisms to assess potential risk to a woman's newborn after birth. This paper engages in an ethnographic content analysis of recommendations regarding pregnancy in key Canadian standards and guidelines for the provision of methadone. Drawing on an understanding of CPGs as based on pragmatic and political concerns, as well as evaluations of 'scientific evidence' (Moreira, 2005), the paper argues that clinical standards and guidelines seek to advance what are often conflicting biomedical, practical and social concerns, which in this case, includes reducing the risks associated with opiate withdrawal during pregnancy, increasing women's willingness to access treatment, and encouraging women to 'self-report' to child protection services during the prenatal period. In this sense, clinical guidelines and standards for the provision of methadone in pregnancy are neither purely technical documents, nor a collection of moral judgements hidden behind the rhetoric of 'evidence', but rather, a means of mobilising the responsibilities of a range of health care actors within a given range of medical and social service arrangements.

### **Toxic Trio Discourse in Social Work Texts; 'Cruel Optimism' for Substance Using Women**

*Radcliffe, P.C.*  
(National Addiction Centre, King's College)

Co-occurring substance misuse, domestic abuse and mental health disorders have increasingly been described as a 'toxic trio' in social work discourse, the combined presence of which are constituted as markers for risk in families. Using discourse analysis and using Lauren Berlant's concept of cruel optimism, this paper critically examines the meanings of toxic trio discourse in English social services department guidance, assessment tools and a range of texts. I consider the history and implications of toxic trio discourse for substance using women who may also be victims/survivors of domestic violence. I argue that one effect of public sector budget cuts is that children and family social work practices in England have become more narrowly focused on child safeguarding surveillance procedures at the same time that women's support and domestic violence services have drastically reduced. Substance using women with complex needs are increasingly less likely to receive support in their own right. At the same time, expectations that substance users will 'recover' and become abstinent within short time scales means that in order to be considered as capable of parenthood, women are required to present as self-managing, 'cleaned-up', models of good motherhood.

## Symposia and Special Events

### Thursday 08 September at 16:20 - 18:00 **MedSoc Committee Event** WHITEHALL 2, CAMS

#### **Conversation Analysis and Medical Sociology: Past, Present and Future Contributions**

**Facilitator: Fiona Stevenson**

The work of the medical sociology community is strengthened by employing a range of approaches (i.e. qualitative, quantitative, policy critique and theoretical development). David Silverman has spoken and written over a number of years about the importance of generating reliable data and valid observations; and linked to this the important lessons that can be learnt from detailed micro analysis of recorded data practiced by conversation and discourse analysts.

In recent years submission of work involving the micro-analysis of medical interactions to the Medical Sociology conference has dwindled. Evidence of a reduction in the range of methodologies available to delegates may limit the growth and vibrancy of debate at the conference and is potentially to the detriment of the discipline. In order to address this potential issue this session considers the potential contribution of conversation analysis for medical sociology and its place in the medical sociology community.

The event will take place on Thursday afternoon between 16:20 and 18:00 and will consist of three presentations from well-known practitioners in the field of conversation analysis; Merran Toerien (York), Alison Pilnick (Nottingham) and Charles Antaki (Loughborough). The first presentation will provide an overview of conversation analysis, the second examples of work using conversation analysis and the third will bring the themes discussed together and address the wider value of conversation analysis for research and in particular medical sociology. The session will be interactive with time allowed for questions and discussion. The data examples presented will focus on the idea of situated decision making.

### Friday 09 September 2016 at 09:00 - 10:40 **Inequalities** STAFFORD 1, CAMS

#### **Understanding Social Inequalities in Health Through the Analysis of Individual and Inter-Sectoral Rehabilitation Trajectories**

In the post-industrial society, health assets seem evermore critical in maintaining or improving ones' social position across different societal fields. In the health field itself, patients demonstrating a healthy lifestyle are likely to obtain a better interaction with health professionals hereby unlocking better services. The case of physical and vocational rehabilitation of patients with incurred brain injuries lends itself to the analysis of such processes. First, patients come from all parts of society, bringing different types of resources (including personal social networks) into the process. Second, the field is spanning the sectors of health and work and welfare, allowing one to see how conceptualizations of health and work may differ in the different institutions involved and how they may differ in valuing various 'qualities' of the patients.

This symposium is intended to comprise four 15-minute presentations, plus 30 minutes of group discussion. The research to be presented reflects on how physical and vocational rehabilitation services are impacted by the patients' resources (health related, cultural and social capital). Furthermore, research is presented that focuses on the institutional logics dominating the different sectors involved. The projects are undertaken in Denmark and Norway. While both approximating a welfare model committed to equality, the two countries are seeing rising social inequalities in health.

#### **Restoring Hope: Strategies Employed by Frontline Workers at Norwegian Local Work and Welfare Offices in Order to Instill an 'Asset-Model' in the Users**

*Havold, O.*

*(Oslo and Akershus University College)*

The share of health related benefits relative to other benefits has risen steadily in Norway the last 20 years. This development causes concern, as those on health related benefits are more prone to become permanently excluded from the labor market. Establishing the Work and welfare administration (NAV) in 2006, replacing employment and social security bodies and parts of municipal social services, was meant to curb this trend. The new agency launched a change in how issues of poor health are approached. Paralleling a development emerging in the field of medicine,

NAV appears to be leaving the 'deficit model' with its focus on hindrances, needs and risk factors – to the favor of the opportunity-oriented 'asset model'. This paper analyses how this critical change is being realized in the concrete casework involving users with severe health problems. The data comes from eight focus group interviews with frontline workers from local NAV offices. The research participants were presented a vignette, a narrative concerning a patient with traumatic brain injury, recently discharged from rehabilitation hospital. The data suggests that frontline workers undertake institutional work, which is 'the purposive action of individuals and organizations aimed at creating, maintaining and disrupting institutions' with their users in order to promote the asset-based perspective. Their aim is to 'restore hope' and motivation through various strategies including positive and 'active' talk (emphasizing opportunities) and the playing on how others perceive the client. The paper discusses what might be at stake in this development, for the part of the users.

### **Social Networks After Severe Brain Injury Rehabilitation – Patients' And Relatives' Perspectives**

*Hindhede, A.  
(Aalborg University)*

Rehabilitation of patients surviving severe traumatic brain injury (TBI) is granted only short courses in specialized departments, followed by discharge to regional municipal rehabilitation. For many of these patients 'community integration' is seen as a critical aspect of successful service provision (Cummins & Lau, 2003). It is often assumed that social relationships will improve or opportunities for forming new relationships will increase, if people are employed or engaged in other productive activity. However, this is not always the case. It is shown that the effect of TBI for patient and their social relations can be devastating (Das-Gupta & Turner-Stokes, 2002) due to the new forms of strain on social networks and families confronted with a lifelong role as informal caregivers. The Bourdieusian understanding of social capital seems critical in maintaining the TBI patients' social position across different societal fields. TBI patients are socially very heterogeneous and for some low positioned patients, this type of capital (especially close family/relatives) might to some degree compensate for lack of cultural and economic capital. In this study, background data from the Danish Head Trauma Database (DHD) is used in a social network analysis of 200 TBI patients 4 years after the brain injury to assess the nature and strengths of social ties (social capital) among patients. Preliminary findings on qualitative interviews with 25 TBI patients will also be presented on how processes of inequality are produced when considering the rehabilitation strategies applied by the patients.

### **What Works in Rehabilitation? - Dominant patients' strategies**

*Guldager, R., Solvang, P.K., Feiring, M., Havold, O.K., Hindhede, A.L.  
(Clinic of Neurorehabilitation/TBI Unit)*

**OBJECTIVES:** In Denmark, as part of the Nordic welfare states equality in social, educational and health care are an ideal. But quantitative studies have shown that high positioned patients in the health care system achieve better treatment and more services e.g. time, examinations than low positioned patients. In this study there is a focus on inequality in healthcare and on how different positioned patients and their relatives act in public healthcare in rehabilitation. In this presentation one high positioned patient and relative is followed during interfaces and critical transitions with the healthcare professions, from time of accident to twelve month follow-up. It is questioned what kind of resources, strategies and negotiations they apply to promote own position and how it is perceived by healthcare professions. This is compared to low positioned patients/relatives. The overall Ph.d.-study aims to sociological investigate rehabilitation trajectories in different adult patients with traumatic brain injury (TBI) and stroke, and to describe mechanisms behind the institutionalized (health care) as part of inequality in health with emphasis on interfaces and critical transitions from time of accident to twelve month follow-up.

**THEORY AND METHODS:** The sociology of Pierre Bourdieu constitutes the theoretical framework and is central to theories structuring. Bourdieu's concepts of economic, cultural, social, health and symbolic capital are used to analyze the patient positions and strategies in the field. The concept of strategy is used to understand how the agents perform to optimize their position in general and also as 'good' patients, relatives and professionals and how they have incorporated the structural conditions. Observation and qualitative interview has been conducted of one patient following the patients' trajectories through different phases of the rehabilitation process during admission at Traumatic Brain Unit. Interdisciplinary meetings are regarded as key elements of the empirical attention.

**RESULTS:** The presented case is a 60 year old female (MK) admitted to rehabilitation after a major car accident. The patient suffers from severe physical and cognitive deficits. MK is married and has 3 grown-up children. MK is an academic and is acknowledged within the field, as well as her husband. They live in a house on three floors. At the admission interview, the husband argues for examinations using the biomedical concepts, classifications and logic and the examinations are accepted. Consequently, it seems like an active resource to act pro-active. As well as it seems like the patient and relative have the ability to use and convert capitals. That means that the couple's knowledge is articulated and used in practice and furthermore that they have the ability to take advantage and make use of it in the rehabilitation process.

**CONCLUSIONS:** Denmark as part of the Nordic welfare states is relatively equal in access to treatment in health care, but inequality is increasing. The case study shows how one high status couple with many resources uses capitals.

## Symposia and Special Events

Especially cultural health capital, cultural capital (including health literacy and ability to use language) and social capital (including family and networks) when interacting with the health and welfare professions in the rehabilitation field. Twenty patients with different status and capitals will be followed during the next year to describe a broader picture of patient's use of capital and of strategies used in Denmark.

### Envisioning the Future

*Koren Solvang, P.*

*(Oslo University College of Applied Sciences)*

**Background:** When a traumatic brain injury occurs future plans need to be reconsidered. Biographical reconstructions are important to the illness work done both by the injured and by professionals providing services. Goal setting and individual plans are key measures in rehabilitation processes. Both injured and professionals identify biographical resources and biographical risks. Past, present and future life contexts are evaluated and processed in efforts to organize life ahead.

**Aim:** Are there differences in how brain injured people and professional service providers envision future life and the rehabilitation process?

**Method:**

Qualitative interviews with injured

Observations of interdisciplinary staff meetings in rehabilitation hospitals

Qualitative interviews with participants in the observed multidisciplinary meetings

Focus Group Interviews with social service case workers who discuss a vignette with a brain injury case.

**Results:** When the processing of biographical data takes place in different worlds; i.e. in individuals' life worlds, and the professional worlds of rehabilitation medicine and street-level bureaucracy, tensions emerge where diverse considerations are weighted in. The individuals have hopes and consider a wide range of alternatives in rehabilitation. The professionals voice a realism in future prospects and represent a narrower set of possibilities in rehabilitation. Ideas among professionals about realism and what can count as sound rehabilitation are in danger of dis-empowering the injured.





# Poster Presentations

Posters will be displayed in the Litchfield Lounge in the Main Building for the duration of the conference. There is a designated poster viewing time: Wednesday 7 September 2016 18:00 – 19:00. Presenters will be available during this time to discuss their work. Posters are listed in alphabetical order by first named author. **Alongside the poster session we are pleased to announce there will be a drinks reception kindly hosted by the Sociology of Health and Illness.**

## SOCIOLOGY OF HEALTH & ILLNESS

### Poster Presentation Prize

Please don't forget to vote for the best poster – each poster has been allocated a number, please refer to this number when completing your ballot slip. Voting slips can be found at the registration desk and the ballot box will be near the posters. Voting will close at 18:00 on Thursday 8 September, and the winning poster will be announced at the conference dinner. The winner will receive £100 worth of SAGE book vouchers.

#### **Nurses' Experiences of Clinical Commissioning Groups: An Observational Study of two Clinical Commissioning Groups (CCGs) in England**

*Allan, H., Savage, J., Lee, G., Dixon, R., Tapson, K., O'Driscoll, M.*  
(Middlesex University)

Clinical commissioning groups were set up under the Health & Social Care Act (2012) in England to commission a range of health and social services. After intense lobbying by the Royal College of Nursing in England, governing body nurses were appointed to these groups to provide nursing leadership to commissioning services. Little is known about how clinical commissioning groups function. An exploratory study of governing body nurses' roles on clinical commissioning groups was undertaken using an observational case study design of two clinical commissioning groups in the South of England. Members of clinical commissioning groups (governing body nurses, finance officers, lay representatives, primary care nurses, members of clinical support units) were observed and interviewed. Data were collected from January 2015 to July 2015.

Findings suggest that there are tensions for all members of clinical commissioning groups in retaining a patient-centred focus despite the rhetoric of both the Royal College of Nursing and the Department of Health. There are difficulties for governing body members in negotiating professional relationships both within and externally to the clinical commissioning group and in the interplay between clinical and non-clinical (lay) authority. Clinical commissioning groups problematise a clinical professionalism based on traditional forms of authority. The authority of governing body nurses remains open to challenge and is unrecognised by members of the CCG and external stakeholders whether it is aligned with a clinical knowledge and practice or with new forms of management and governance.

#### **The Experiences of Patients with Cancer and Their Use of Traditional Medicine (TM) in Brong-Ahafo Region of Ghana**

*Appish, I., Arber, A., Magnusson, C.*  
(University of Surrey)

An estimated 75% of the worldwide population and 70% -80 % of the African population use Traditional Medicine (TM) for therapeutic reasons. The use of TM/CAM by cancer patients is on the surge in recent times. The study explores the experiences of cancer patients who have used or are using TM in Ghana using a grounded theory approach. The study aims to interview up to thirty-five participants in two hospitals and traditional medical, or herbal facilities; twenty-two have been interviewed.

The preliminary findings are that cancer patients derive benefits such as easy accessibility, relief from symptoms and being able with TM. Also, cancer patients experience dignity, respect, and effective/supportive communication from the traditional medical or traditional herbal practitioners (TM/THP).

On the contrary, cancer patients find it difficult in accessing conventional or biomedicine because of lack of affordability of treatment/drugs and proximity to treatment facilities within their communities. Also, cancer patients experience embarrassment, lack of dignity and respect, lack of good communication and interpersonal or professional relationship within conventional medicine. Furthermore, cancer patients experience bureaucracy, longer queuing and waiting times and nepotism (whom you know, who you are) at the conventional medical facilities and practitioners (CM/CMP).

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The findings highlight the role that TM plays in cancer patients' lives and some of the reason they would choose TM over conventional medicine. In addition, the findings play into the whole debate on the care cancer patients require throughout their disease trajectory i.e. a targeted pathological treatment and/or holistic care approach.

### **Interrelations between Mass Opinion, Public Health and Preventive Medicine: A New Approach to Predictive Patterns Behavior Analysis as a Basis for a Future of Comparative Survey Research**

*Gabriele Muñiz, J.*  
(University of Barcelona)

The conceptualization of mass opinion applied to health arena is by no means a simple matter. One possible way to think about it is that public health opinion is a social construction, a microcosm on a large scale of the problems created by globalization phenomenon. Since mass opinion affects public health representation, it becomes important to find what mass opinion on public health is formed and how it changes. Some argue that the way that society is structured along race, class, and gender lines negatively impacts public health perception. Despite this, the surveys and other sociological studies have forced a revision in the analysis of public opinion related to health issues, out of dominant explanatory variables (self-rated health, education and economics). That is, substituting the rigid and one-dimensional concept of an 'individual health' based on one 'public opinion' by a more flexible and variegated view of the 'social' based on that everybody doesn't hold the 'same opinions'. Whilst there has been a long tradition in medical sociology of understanding illness and its related behaviours within their relevant social contexts, little work has been carried out regarding the influence of public opinion and social health perceptions on preventive medicine attitudes and patterns. From this point of view we explain the role of public opinion through the construction of new predictive patterns behavior by focusing on the relevance of public health and preventive medicine perception as dependent variable.

### **Perceptions of Clinical Research Participation Among Breast Cancer Women in Spain: A Qualitative Multicenter Study Based on the Theory of Planned Behavior. SOLTI Breast Cancer Research Group Qualitative Research**

*Gabriele Muñiz, J., Gabriele G., Fernandez, L., Casas, A., Ciruelos, E., Ortega, V., Soberino, J., Balmaña, J., Herrera, A.*  
(SOLTI - Academic research group in breast cancer)

The aim of this study was to identify distinct patterns of reasoning process followed by female breast cancer patients previously to decide participate, refuse or leave clinical trials, within the theory of planned behavior framework. The election of this methodology was motivated for elucidating and better understanding the complexity of factors influencing patient perception, behavior and decision-making process in clinical trials. This research, the first of its kind in Spain, is part of a larger study employing both qualitative and quantitative methods. The qualitative phase consisted of six semi-structured interviews with leading experts in clinical oncology research, followed by four discussion groups involving thirty-nine breast cancer patients with and without disease relapse, metastases, stage I-IV disease, and adjuvant and neoadjuvant supportive therapy. Focus groups were conducted at four of the leading clinical research university reference hospitals. Despite limitations of sample size, the study did have several key findings with respect to breast cancer clinical trials-related beliefs and the level of supporting of personal autonomy granted and experimented by women participants in clinical trials among key determinants. The greater the imbalance between the clinical process and perception, the greater and more persistent was the subjective loss of the reference parameters of patient psychological-emotional state and quality of life.

### **The Semiotics of Suffering: How Triage Nurses Make 'Objective' Pain Assessments**

*Johannessen, L. E. F.*  
(Oslo and Akershus University College of Applied Sciences)

Pain is widely considered a subjective experience; yet in emergency medicine, triage nurses have to make an 'objective' assessment of the intensity of patients' pain to determine their place in line to see a physician. The present paper draws on data from a fieldwork study of a Norwegian emergency primary healthcare clinic (EPHC) to analyse how triage nurses performed pain assessments. Nurses in the EPHC were required to quantify their assessments on a scale from 1-10 based on patients' own report and observable signs of pain. The paper shows that nurses seldom asked patients about their 'subjective' score; instead, they relied solely on their 'objective' estimation. They acknowledged the subjective nature of pain but emphasised that 'subjective' scores were unsuitable for determining patients' relative priority. Nurses based their 'objective' scores on a widespread array of medical and non-medical signs, and their pain assessments were mediated by variables such as patients' age, gender and perceived cultural background. By analysing nurses' interpretive practice, the paper contributes to our understanding of triage assessments and nursing epistemology and sheds light on a source of arbitrariness in nurses' priority setting that might be highly consequential for patients.

### **Knowledge Mobilisation by Advanced Nurse Practitioners in Discharging Patients from the Emergency Department: An Ethnographic Study**

*King, R.*  
(University of Sheffield)

Nurses use many sources of knowledge in clinical decision-making, including local guidelines, advice from colleagues, courses, experience, new treatments, publications, tacit knowledge, and the internet. Patient care can be improved when they apply research to practice, however studies have identified an under-use of research. Knowledge mobilisation (KM) is concerned with closing the gap between research and clinical practice, and improving research dissemination and implementation. Little is known about KM by ANPs.

This study will focus on how ANPs use knowledge to discharge patients with long term conditions from the ED. LTCs are increasing and place a significant burden on emergency care. Advanced nurses are part of the government's strategy to improve emergency care services.

Ethnographic methods of observation and in-depth interviews will be used. There will be two phases to the study; to understand the ANP role and ED context, and to explore knowledge mobilisation by ANPs. Gabbay and Le May's (2004) theory of clinical mindlines in primary care will be explored in the context of ANP decision-making in the ED.

The findings will increase our understanding about knowledge mobilisation by ANPs in discharge decision-making. This will help to improve research dissemination by clinical educators and researchers. By improving the communication of new research findings, patients will benefit from healthcare that is informed by the best available evidence. There may also be a cost benefit; if the outcome of improved knowledge mobilisation leads to a reduction in hospital admissions.

### **Exhibiting Pain: Using Creativity To Communicate Persistent Physical Pain**

*Main, S.*  
(Open University)

As an invisible and subjective condition, persistent pain can prove a challenge to communicate and understand. However, a lack of understanding may undermine the ability of health care professionals and informal support networks to respond effectively to the person with pain. With the increasing recognition of this condition, there is a need to develop new methods of conveying the nature and impact of that pain for the individual.

An alternative means of expressing the persistent pain experience is through creative techniques, such as the visual arts or in writing. In this study online exhibitions, displayed using social media, are being used to explore the interpretation of creative representations of persistent pain. One aim is to examine how these may aid a person's communication of their pain experience with health care professionals, friends and family.

Analysis of the responses to the exhibits highlights the symbols and signs (semiotics) that are used by audiences to construct particular interpretations. Overall, the intention is to gain insight into the understandings of persistent physical pain that are constructed through the viewing of creative representations. The interpretations will be considered according to audience demographic and/or within the context of discussion with other exhibition visitors. This paper explores the emerging interpretations of the exhibits and considers the findings in the context of communicating the pain experience.

### **Engaging Communities to Improve Mental Health in African and African Caribbean Groups: A Qualitative Study Evaluating the Role of Community Well-being Champions**

*Mantovani, N., Pizzolati, M., Gillard, S.*  
(St George's, University of London)

Over the last decade Britain has undergone reforms to promote engagement in local structures of governance. These reforms have encouraged the promotion of active citizenship and have been central to the government's public service modernisation agenda. This poster presents the findings from a study evaluating a pilot outreach intervention which adopted a community engagement model to address the mental health needs of African and African Caribbean groups, which entailed a partnership between Faith Based Organisations (FBOs), local public services, and community organisations (COs) to co-produce the pilot project. Lay people were trained to raise awareness about mental health among these communities in South London. Between 2012 and 2013 a qualitative participatory approach was used to evaluate the pilot project, which enabled a researcher to take part in the engagement phase of the pilot project, and the project coordinators to be involved in the research process. Semi-structured, one-to-one interviews were carried out with 13 Community and Well-Being Champions (CWBCs) recruited from African and African Caribbean communities (seven male and six female) which were analysed thematically. This study examines the impact of the relationship between the intervention and community through the participants' engagement in the pilot outreach project and the action undertaken as champions. We found that although CWBCs used circles of influence to share ideas about mental health and well-being and to encourage change, they encountered resistance on the part of the people they engaged with, which resulted from a lack of knowledge about mental health, taboos and ascribed stigma.

## Poster Presentations

### **Making Sense of Genito-Urinary Symptoms: A Mixed Methods Study**

*Mapp, F., Hickson, F., Mercer, C., Wellings, K.*  
(London School of Hygiene and Tropical Medicine)

#### Background

Genito-urinary symptoms can indicate underlying infection or disease requiring prompt treatment. However symptoms are subjective and non-specific and may not be interpreted as a need for healthcare by those who experience them. Drawing on Zola's work about symptoms and care-seeking, I explore lived experiences of genito-urinary symptoms and sense-making processes that give meaning to bodily sensations.

#### Methods

I used an explanatory sequential mixed methods design to combine data from Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) with a dominant qualitative component comprising 27 semi-structured interviews. The qualitative sample was drawn from Natsal-3 participants who reported genito-urinary symptoms and non-attendance at sexual health clinics to explore symptoms outside of medical settings. I calculated symptom prevalence estimates and used principles of Interpretative Phenomenological Analysis to explore sense-making, symptom meanings and lived experiences.

#### Results

From a total of 8,947 sexually experienced survey participants aged 16-44, 21.6% (95% CI 20.4-22.9) of women and 5.6% (95% CI 4.9-6.6) of men reported recent symptoms. Using qualitative interview data I problematized quantitative prevalence estimates and developed an innovative explanatory mechanism for symptom sense-making processes centred on a 'cause-concern cycle.' Meanings were imported from information sources or created by participants and transformed bodily sensations into symptoms although sensations were often normalised, especially by women. Genito-urinary symptoms had physical, emotional and existential components.

#### Conclusions

Genito-urinary symptoms are more commonly reported by women than men, however the meanings attributed to bodily sensations mediate interpretation of the experience and subsequent decision-making and healthcare-seeking behaviour.

### **Does Subjective Social Status Vary the Effects of Socioeconomic Status on Sleeping Problems? Analysis of Social Survey Data in the Area Afflicted by the Great East Japan Earthquake**

*Misawa, J.*  
(Nihon University)

The Great East Japan Earthquake in March 2011 seriously impacted sleeping problems (SP) of residents in the afflicted area. We suggest that socioeconomic status (SES) including income and educational levels is related to SP in the area. However, subjective social status (SSS) could vary the relationship, because SSS might not necessarily coincide with SES. Therefore, we aimed to elaborate the relationship among SP, SES, and SSS. Of the residents in the disaster area, 2,100 aged 20 years or older, were surveyed in November, 2011. Of the 1,532 answers obtained (a 64% response rate). Controlling for demographic characteristics, social support, anxiety about social life, experiences of moving, and amount of damage incurred, we created a logistic regression model to test for an association between SP and SES by each SSS (high, middle and low class). The model showed that high educational level in the low SSS class was associated with reduced odds of SP. On the other hand, a high income in the middle SSS class was associated with increased odds of SP. In the high SSS class, SES was not associated with SP. These results suggest that SSS varies the relationship between SP and SES. High educational levels would be helpful in preventing SP in the low SSS class. Additionally, we speculate that the middle SSS class might experience SP by managing to maintain its status in a situation in which a high income group would feel threatened, because those who rate their own status as in the middle may value income more highly.

### **'I'm not a couch potato': Older Adults' Construction of Sedentary Behaviour as a Moral Practice**

*Palmer, V., Fitzsimons, C., Wyke, S., Mutrie, N., Gray, C. on behalf of the Seniors USP consortium*  
(University of Glasgow)

Engaging in prolonged sedentary behaviour (SB) has been linked with physical and mental health risks, particularly among older adults. There is a need to explore how older adults understand SB in their everyday lives.

As part of larger interdisciplinary study examining SB in older adults (Seniors USP), 42 semi-structured interviews were conducted with older adults of varying age (mid 60s/late 70s/mid 80s), social class and objectively-measured SB.

Older adults provided accounts of sitting which constructed their sitting as 'busy': 'I suppose the thing they didn't go into at all was what you did when you were sitting down, because I tend to be quite active and, you know, I'm on the train quite a lot, on the bus quite a lot going places, now this doesn't seem to matter, you know, that's you just sitting'. Thus participants distinguished between being busy or not busy rather than being sedentary or physically active 'You know, I'm not sitting there doing absolutely nothing which is the main thing for me – I'll try and do something'. In addition these older adults distanced themselves from the sedentary 'other' 'there's a lot of folk just sit down, and that's

it, they're not even going to try'. In doing so, they construct identities as busy sitters situating sitting as a moral practice and constructing themselves as 'active' citizens.

Understanding the way older adults construct sitting as a moral practice has implications for the design and development of future interventions to reduce or break up SB.

### **MSK Injury Sustained Through Exercise: Patient Pathways, Social and Economic 'Costs' and Medical Interactions**

*Pullen, E., Malcolm, D., Wheeler, P.  
(Loughborough University)*

Musculoskeletal injuries (MSK) sustained through exercise/physical activity (PA) have been identified as accounting for up to 30% of all primary care consultations, creating an increased workload to primary care and resulting in suboptimal injury management and general patient dissatisfaction. The recent establishment of Sport and Exercise Medicine (SEM) within NHS England seeks to reduce this workload through its primary initiative of providing a single point of referral from primary care into specialist MSK secondary care, ensuring this patient pathway and transition is efficient. At present, very little is known about the pathways of patients with an MSK injury sustained through PA, and even less about the extent SEM has been integrated into these pathways to provide a seamless patient journey. Addressing this lacuna in the research, this presentation illustrates the findings from PhD research that shed light on the pathways of patients with an MSK injury sustained through PA up until the point they receive treatment at one SEM clinic in NHS England. Employing a qualitative methodology, this research demonstrates the extent SEM initiatives are being developed in the NHS and effectively used as means to reducing the workload to NHS services and improving patient satisfaction. It provides evidence of the patient experience in these pathways and the potentially more problematic implications inefficient patient pathways have for the social economy and health promotion policy.

### **Entangled Medical Treatment: A Network Approach of Traditional and Biomedical Health Care Providers in the Kathmandu Valley**

*Rössl, L.  
(Danube University Krems Department Für Migration And Globalization)*

*The here introduced study is based on the empirical findings of two research stays in the Kathmandu Valley/ Nepal of 14 months total (2009, 2012). The research questioned if the medical plurality is reflected in cooperation and relations between health care practitioners of traditional and biomedical health care professions with different concepts about illness and treatment. It was addressed, which actors are included or excluded in processes of medical pluralistic network construction, and what are underlying conditions for participation. In this sense politics and policy making demonstrated relevance for treatment decisions, status and options of health care providers.*

*The "Mixed Methods Research Design"(1) framed the complemented application of qualitative interviews, observations and standardized questionnaires. The implemented egocentric network approach focused on the representation of medical pluralistic networks.*

*Oriented towards Kleinman and Chrisman's(2) model of the "health-seeking process" of patients that includes social networks and social and cultural factors, empirical findings are contextually understood: personal networks are considered embedded in treatment-seeking processes of health care practitioners. This research shall contribute to the knowledge about the impact of medical pluralism in Kathmandu Valley and fosters the understanding of processes and characteristics of medical pluralism in a dynamic changing society.*

*(1) Creswell, John et al. (2003): Advanced Mixed Methods Research Designs. In Handbook of Mixed Methods in Social & Behavioral Research. Abbas Tashakkori/ Charles Teddue, eds.*

*(2) Chrisman, Noel/ Kleinman, Arthur (1983): Popular Health Care and Lay Referral Networks. In Handbook of Health, Health Care, and Health Professions. David Mechanic, ed.*

### **Supply-side Barriers to Maternal Healthcare Utilization: A Study of Health Sub-Centres in Rural India**

*Singh, A.  
(University of Portsmouth)*

Background: Publicly-funded health facilities in the developing world face several types of barriers in delivering quality health services. The availability of resources (physical infrastructure, human resources, training, drugs, and equipment) may significantly affect the volume and quality of services provided. Therefore, this study investigates the effect of supply-side determinants of maternity care provision at health sub-centers (HSCs) in rural India.

Data and Methods: Using data from District-Level Household Survey 2007–2008, the examines the effect of supply-side variables on the utilization of antenatal, postnatal and in-facility delivery services provided at HSCs. Due to the count and over-dispersion properties of outcome variables, data has been analysed using negative binomial regression model.

Results: The number of safe deliveries reduces in HSCs with no labor table (Incidence Rate Ratio ((IRR))=0.45; P=0.00) and bed-screen (IRR=0.70; P=0.00) and a contractual nurse-midwife (IRR=0.76; P=0.04). The availability of village health and sanitation committee (VHSC), tap water supply, telephone, functional toilet, regular electricity supply increases the volume of MCH services, even after controlling for catchment area population, region, religion, maternal

## Poster Presentations

education, economic status, and district-level fertility rate. The same is true for essential obstetric drugs, blood pressure equipment, and examination table as well. Conclusion: The Government of India, to improve the health services utilization at HSCs, should invest in basic infrastructure, essential drugs, and equipment at all sub-centres. Since contractual ANM does not appear to be as effective as a permanent ANM, the policymakers should look deeper into the causes behind such anomaly.

### **Shortage and Distributional Inequalities of Specialists at Rural Hospitals in Uttar Pradesh, India**

*Singh, A.*  
(University of Portsmouth)

**Background:** The study aims to examine shortage and distributional inequalities of specialists (relevant for maternal and child health) at the rural hospitals in Uttar Pradesh (UP) state of India.

**Data and Methods:** The study uses the latest rounds of District Level Household Survey to assess the shortage and distributional inequality of specialists in rural hospitals during 2002-03 and 2007-08 by employing a perfectly decomposable measure of inequality known as Theil 'T' along with the Gini coefficient. Negative binomial regression was used to examine the association of facility characteristics with the availability of specialists.

**Results:** More than 75% rural hospital do not have pediatricians and anesthetists and a little over two-thirds do not have obstetricians and surgeons. Only 4% have all four specialists, and 48% have no specialists at all in 2007-08. Among health workers at rural hospitals, only specialists record an increase (51%) in inequality as measured by Gini during 2002-07. The contribution of 'within-district' inequalities (81.8%) outweighs the 'between-district' inequalities (18.2%). The eastern and southern UP districts are not only deficient regarding the availability of specialists but also, their current distribution is highly unequal. Rural hospitals with residences for specialist, electricity, and tap water are expected to have more specialists.

**Conclusion:** Distributional inequalities further complicate the already existing huge shortage of specialists in rural hospitals of UP. The Government must take corrective actions in this regard with a focus on eastern and southern UP. Equipping rural hospitals with basic amenities and residential facilities might help reduce distributional inequality.

### **Parents' Attitudes Toward Participating Children's Informed Assent in a Birth Cohort Study**

*Suda, E., Muto, K., Ri, I.*  
(National Institute for Environmental Studies)

The Japan Environment and Children's Study (JECS), a birth cohort study involving 100,000 parent-child pairs, was launched in 2011 in order to evaluate the impact of various environmental factors on children's health and development. Health outcomes and exposure measurements will continue until the participating children become 13 years old. Proxy consent was obtained from a pregnant mother regarding her baby's research participation.

Ethical Guidelines for Medical and Health Research Involving Human Subjects (MEXT and MHLW, 2014) require confirming an informed assent (IA) from a child participating in a research in the age he/she can understand about the research and express his/her will. We conducted a research to clarify the attitudes of JECS participating children's parents who are expected to get involved in the IA process from the early stage.

The semi-structured individual interviews with 20 mothers and 5 fathers were conducted. One of the parents' main incentives for participation was that they would like to provide something goods for their own child, his/her generation or next generations. Parents wanted to explain about their wish to participating children, and this seemed to be one of the reasons which make parents' attitudes positive toward IA. Also the trust toward JECS implementing organizations or persons was observed as a base of parents' sense of security and safety regarding their children's participation. This seemed to ease parents' hesitation toward IA.

The meanings, significances and challenges of IA for the birth cohort studies, participating children and their parents will be discussed.

### **Professional Identity in Nursing: UK Students' Explanations for Poor Standards of Care: A Focus Group Study**

*Traynor, M., Buus, N.*  
(Middlesex University)

Professional socialisation in medicine and nursing is acknowledged to involve anxiety. In nursing it is widely seen to involve a loss of idealism, which is often considered a negative consequence by researchers. This study set out to re-examine the topic focussing on the development of professional identity. Six focus groups from 2013-6 were held with a total of 49 2nd and 3rd year BSc nursing students from three cohorts studying at a university in London, UK and their transcripts were subject to discourse analysis and informed by ideas of identity as interaction and linguistic practices. Participants' talk was strongly dualistic and inflected with anxiety. Participants identified with caring as an innate characteristic. They described some qualified nurses as either not possessing this characteristic or as having lost it. They explained strategies for not becoming corrupted in professional practice. Their talk enacted distancing from 'bad' qualified nurses and solidarity with other students. Their talk also, apparently paradoxically, featured

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cynicism. Neophyte nurses' talk of idealism and cynicism needs to be understood as identity work in the context of anxiety inherent in the work of nurses and in a relatively powerless position in the professional healthcare hierarchy.

### **Reconsider the Notion of Professionalism of Home-Visiting Nurse in Terms of Integrated Community Care**

*Tsumura, I., Tomomatsu I., Honma T., Yoshimura, S.*  
(Tokyo Medical and Dental University)

Aim and background

This study aims to reconsider the notion of professionalism of home-visiting nurse in terms of integrated community care.

Aging of the population has acutely proceeded in Japan. In 2013, the number of the population who are 65 years or older reached to 25%. In order to overcome issues in aging society, Japanese government proposes integrated community care. Under the community care scheme, nurses are expected to have more roles which are different from the conventional roles.

Method

Based on review of advanced cases of community based care, five municipal corporations and five medical organizations are chosen for interview. As of them, in total 20 people were interviewed by using semi-structured face-to-face interviews techniques. All interviews were recorded and thematically analysed. As of them, this study specifically focuses on one home-visiting nurse station in Tokyo.

Result and discussion

Home-visit nurses make significant roles for active aging. They are involved in community activities which are not considered as professional tasks of nurses in the existing hospital based setting. They are demanded to play a key role in their town's events by local government if they want to propose some opinions to public administration. It is vital that issue are carried out on the premise that they have enough knowledge of local area. I argue that their current experiences in integrated community care propose elements to reconsider the professionalism of home-visiting nurses.

### **Chronic Illness, Ageing and Gender: An Exploratory Investigation of Experiences and Motivations for Sustained Involvement in Community Cardiac Rehabilitation**

*Vaittinen, A., Kaner, E., Stobart, L.*  
(Newcastle University)

This presentation will consider some preliminary findings of an exploratory study examining the gendered experiences of ageing with chronic illness (CVD) in the context of physical activity (PA) based cardiac rehabilitation (CR). The study utilised qualitative methods namely participant observation and qualitative interviews.

Recent research has recognised the potential of physical activity in facilitating older adults resistance to negative stereotypes of ageing and illness (Allen-Collinson, 2011; Evans & Sleaf, 2012). However, qualitative research on experiences of physically active, ageing body in recovery and management of chronic illness is limited (Evans & Crust, 2015). Furthermore, a recent meta-synthesis of qualitative studies into CR highlighted the need for more theoretically driven research into influence of gender, and other intersecting social positionalities to the uptake of and adherence to CR (Angus et al., 2015).

The aim of the presentation is to offer preliminary insight into the participants' perceptions of CR in relation to how gender shapes their experiences of the ageing body and chronic illness and to explore and learn from the participants' motivations for sustained involvement in CR progression groups along with understanding the difficulties they may have experienced. The focus is on the subjective and interpersonal elements of the ageing body in CR and the manner in which physical activity based cardiac rehabilitation in particular, contributes to ageing well.

Theoretically the discussion is framed by the 'intersectional approach' (Brah & Phoenix, 2004), which facilitates understanding of the participants' experiences at the nexus point of ageing, gender, chronic illness and physical activity.

### **Cooperative Design in the Development of an Early Therapy Intervention for Perinatal Stroke (eTIPS)**

*Watson, R., Pearse, J., Rapley, T., Baggaley, J., Basu, A.*  
(Newcastle University)

Perinatal stroke is the leading cause of hemiplegic cerebral palsy, with life-long personal, social and financial consequences. Early therapy has the potential for significant improvements in long term outcome. By involving families and health professionals in the development and design stage, we aimed to produce a workable intervention which they would engage with.

9 parents of children with a hemiplegia and 14 health professionals involved in care of infants with stroke took part in peer review and three focus groups to discuss evolving materials and concepts, with revisions made iteratively. Focus group data were coded using Normalisation Process Theory (NPT).

eTIPS was well received: participants offered suggestions to modify and improve it. Health professionals and parents saw eTIPS as different from usual practice and valuable (high coherence); seemed keen to engage (high cognitive participation); felt the range of tasks parents are asked to undertake was very workable (high collective action); had

## Poster Presentations

trust in eTIPS and that parents would undertake activities (high collective action); saw eTIPS as flexible and adaptable (high reflexive monitoring). Following suggestions made, we added a section on involving the extended family, and obtained further funding for a website and videos to supplement written materials.

Focus groups with parents and health professionals provided meaningful feedback to iteratively improve the eTIPS materials prior to a pilot study. eTIPS has a high potential to normalize and become a routine part of parents' interactions with their child.

# BSA MedSoc Regional Groups

There are a number of MedSoc Regional Groups around the UK that regularly organise local events. Joining one is a great way to meet colleagues in your area and stay linked in to the MedSoc community throughout the year.



## Find out if there's one near you?

### Existing Regional Groups:

#### East Midlands

Contact: Nicky Hudson [NHudson@dmu.ac.uk](mailto:NHudson@dmu.ac.uk)

#### London

Contact: Oliver Bonnington [ollie\\_bonnington@hotmail.com](mailto:ollie_bonnington@hotmail.com)

#### North West

Contact: Donna Bramwell [Donna.Bramwell@postgrad.manchester.ac.uk](mailto:Donna.Bramwell@postgrad.manchester.ac.uk)

#### North East

Contact: Janet Shucksmith [j.shucksmith@tees.ac.uk](mailto:j.shucksmith@tees.ac.uk) or Stephanie Scott [steph.scott@ncl.ac.uk](mailto:steph.scott@ncl.ac.uk)

#### Scottish

Contact: Suzanne Grant [smgrant@dundee.ac.uk](mailto:smgrant@dundee.ac.uk) or Sara MacDonald [sara.macdonald@glasgow.ac.uk](mailto:sara.macdonald@glasgow.ac.uk) or Shona Hilton [shona.hilton@glasgow.ac.uk](mailto:shona.hilton@glasgow.ac.uk)

#### South Coast

Contact: Flis Henwood [F.Henwood@brighton.ac.uk](mailto:F.Henwood@brighton.ac.uk) Catherine Will [c.will@sussex.ac.uk](mailto:c.will@sussex.ac.uk) or Catherine Pope [C.J.Pope@soton.ac.uk](mailto:C.J.Pope@soton.ac.uk)

#### South West

Contact: Gayle Letherby [gayle.letherby@plymouth.ac.uk](mailto:gayle.letherby@plymouth.ac.uk) or Anthony Gilbert [anthony.gilbert@plymouth.ac.uk](mailto:anthony.gilbert@plymouth.ac.uk)

#### Wales

Contact: Julie Latchem [LatchemJM@cardiff.ac.uk](mailto:LatchemJM@cardiff.ac.uk)

#### West Midlands

Contact: Geraldine Brady [g.brady@coventry.ac.uk](mailto:g.brady@coventry.ac.uk)

#### Yorkshire

Contact: Barry Gibson [b.j.gibson@sheffield.ac.uk](mailto:b.j.gibson@sheffield.ac.uk)

## If there isn't one near you, why not start one?

The MedSoc Group Committee is keen to support the establishment of new Regional Groups and the revival of currently inactive groups. Funding is available on an annual basis to support events and networking. If you would like more information please contact Claire Simmons [Claire.simmons@britsoc.org.uk](mailto:Claire.simmons@britsoc.org.uk) or why not come and see her at the registration desk during the conference.

# BSA MedSoc Special Interest Groups

There are currently four MedSoc Special Interest Groups. Joining one is a great way to meet colleagues with similar research interests throughout the year.

## Existing Special Interest Groups:

### Applied Qualitative Health Research (AQHR)

Contact: Tim Rapley [tim.rapley@ncl.ac.uk](mailto:tim.rapley@ncl.ac.uk) or Cath Exley [catherine.exley@ncl.ac.uk](mailto:catherine.exley@ncl.ac.uk)

### Deconstructing Donation

Contact: Laura Machin [l.machin@lancaster.ac.uk](mailto:l.machin@lancaster.ac.uk)

### Environment and Health

Contact: Richard Compton [richard.compton@kcl.ac.uk](mailto:richard.compton@kcl.ac.uk) or Nick Fox [n.j.fox@shef.ac.uk](mailto:n.j.fox@shef.ac.uk)

### Sociology of Mental Health Study Group

Contact: Rich Moth [mothr@hope.ac.uk](mailto:mothr@hope.ac.uk)

## Get in touch if you have an idea for a Special Interest Group

The MedSoc Group Committee is keen to consider proposals for Special Interest Groups. Funding is available on an annual basis to support events and networking.

For further details about running a MedSoc Regional or Special Interest group please contact Claire Simmons, BSA Membership Development Officer, [Claire.simmons@britsoc.org.uk](mailto:Claire.simmons@britsoc.org.uk)



## Critical Public Health

### WHITEHALL 2, CAMS

Wednesday 07 September 2016 at 12:45 - 13:50

#### **The Knowledge and Attitudes of UK University Students in Relation to Ultraviolet Radiation (UVR) Exposure and their Sun-Related Behaviours: A Qualitative Study**

*Kirk, L., Greenfield, S.*  
(University of Birmingham)

Malignant melanoma is the fifth most common cancer in the UK and rising. With advances in accessibility to go abroad and use sunbeds, combined with the popularity to acquire a tan, young adults' sun-related behaviours are significantly increasing their risk of skin cancer. Understanding their knowledge and attitudes towards these behaviours would be key for developing effective skin cancer prevention campaigns. While existing evidence suggests appearance and health-related motives encourage the preference for tanning over sun-protection, evidence is inconclusive on whether knowledge affects sun-related behaviours. Equally, literature on attitudes has not been qualitatively studied in-depth pertinent to UK male and female students. 15 students from a UK University were individually interviewed to explore whether their knowledge on the harms of ultraviolet radiation influences their sun-related behaviours and to examine their attitudes towards: sun-protection, natural and artificial tanning behaviours. With thematic analysis using the Framework Method, analyst triangulation and member validation, five themes emerged. Knowledge did not strongly influence sun-related behaviours. Body image (Slade 1994) strongly motivated participants' sun-protection, natural and artificial tanning practices where implications on appearances affected self-confidence, owing to external influences from: peers, media and family. Unrealistic optimism appeared key in governing decisions towards harmful behaviours whereas perceived susceptibility (Health Belief Model; Becker 1974) to sunburn encouraged sun-protection. Overall, attitudes towards sun-related behaviours are multi-dimensional with influences linked, indicating the diversity of potential areas to be addressed for skin-cancer prevention. Public Health strategies may benefit from appearance-related campaigns, encouraging safer parental sun-related habits and correcting sun-related misconceptions.

#### **From Lifestyle Programme to Changing Social Practice: An Illustration from Football Fans in Training**

*Wyke, S., Hunt, K., Bunn, C., Gray, C.M.*  
(University of Glasgow)

Recent theoretical developments constitute social practices as the integration of meanings, materials and competencies, and distinguish between practices as entities (a 'recognisable doing that is relatively stable') and practices as performance (the specific enactment of a practice by carriers)<sup>1</sup>. In summarising these developments Maller<sup>2</sup> suggests they offer useful purchase on how to intervene to improve public health.

This paper investigates the usefulness of the developments to understand lifestyle changes made by men aged 35-65 taking part in a group-based weight management programme delivered through football clubs, Football Fans in Training (FFIT). A randomised controlled trial in 13 clubs showed FFIT was effective in supporting long-term weight loss. Data from focus groups conducted immediately post-programme and 12 months after baseline measurement were analysed in relation to what was said about changes in meanings, competencies and the influences of materials. By participating in FFIT and interacting with other men in the football setting, men constructed new meanings for practices such as eating breakfast or walking more. For many, these practices were adopted as signifiers of 'men who cared about health', became taken for granted and embedded in everyday life. The programme introduced new competencies such as self-monitoring or reading food labels which were reported as powerful tools. The programme materials (the pedometer, club-branded programme guide and t-shirt, the stadium itself) were critical. The focus groups showed that repeated performance of practices whilst on the programme enabled their 'carriage' over time, enabling sustained change in the practices themselves after the programme ended.

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# Ethnicity

## WHITEHALL 3, CAMS

**Wednesday 07 September 2016 at 12:45 - 13:15**

### **Being Invisible: Understanding the Experiences of the South Asian Population and Dementia Service Provision**

*Atcha, M., Bingley, A., Keegan, T., Froggatt, K., Barnsley, K.*  
(Lancaster University)

People from the South Asian population are observed to have an elevated risk of developing dementia, related to a high incidence of diabetes and hypertension. However, this population appears to be under-represented in dementia research and service provision. The disparity between the prevalence of people with dementia and the reported incidence of dementia, especially among South Asian populations (United Kingdom's largest ethnic minority), is of concern to public health service providers. This paper reports on mixed-methods doctoral research that aimed to identify the social and cultural issues affecting the decisions of people with dementia and their families in the South Asian population in Blackburn with Darwen (BwD), seeking health and social care support.

The research involved two phases: Phase 1 assessed the incidence of dementia in BwD by age, sex, and ethnicity. Phase 2 used qualitative methods to explore how members of the BwD South Asian population perceived dementia and those with relatives with the condition engaged with local dementia care services. Data was collected via three focus groups with people involved in a community project; dyad interviews with people living with dementia and their families; and interviews with healthcare professionals working in dementia services.

Early findings suggest negative perceptions of dementia strongly influenced by cultural beliefs, resulting in people with dementia being hidden away by their families. This may explain why health professionals report that this population seek help late in the illness, and there is an argument for public health services to develop culturally relevant outreach programmes based on Alzheimer's Society 'Dementia Friendly Communities'.

### **Exploring the Relationship Between Stigma and Help-Seeking for Mental Illness in African-Descended Faith Communities in the UK**

*Mantovani, N., Pizzolati, M., Edge, D.*  
(St George's, University of London)

Stigma related to mental illness affects all ethnic groups but is especially prevalent in minority communities and is known to contribute to the production and maintenance of mental illness and to restrict access to care and support, thereby potentially increasing disparities. Little is known of the links between stigma and help-seeking for mental illness in African and Caribbean populations.

Building on the evidence that Faith-Based Organisations (FBOs) can aid the development of effective public health strategies, this qualitative study used semi-structured interviews with faith communities of African descent to explore the complex ways in which stigma influences help-seeking for mental illness in these communities. A thematic approach to analyse the data was applied to the entire data set.

Twenty-six men and women who had varying levels of involvement with FBOs in South London were interviewed (e.g. six faith leaders, thirteen 'active members', and seven 'regular attendees').

The factors found to influence help-seeking behavior in African-descended communities were: beliefs about the causes of mental illness; 'silencing' of mental illness resulting from heightened levels of ideological stigma in these communities; and stigma (re)production and maintenance at community level. Individuals with a diagnosis of mental illness are likely to experience a triple jeopardy in terms of stigma – rejection by their families, stigma and alienation from their communities and internalised 'self-stigma'.

'One-size-fits-all' approaches cannot effectively meet the needs of diverse populations. Barriers to help-seeking for mental illness could be removed through active engagement of service users, families and community members in co-producing services.

## **Experiences of Health and Illness**

### **G63, MAIN BUILDING**

**Wednesday 07 September 2016 at 12:45 - 16:10**

### **Dualities of Dementia Accounts: Biographical Reconstruction and Narrative Economies**

*Hillman, A., Jones, I. R.*  
(Cardiff University)

Recently Marian Burchardt (2015) has referred to 'narrative economies' as a set of exchange relationships that, through biography and story-telling, facilitate access to resources and act as a source of symbolic and material value. This paper draws on findings from a pilot study undertaken as part of the ESRC funded project 'Improving the experience of dementia and enhancing active life' (IDEAL) and explores how biographical accounts by dementia patients and carers (re)produce important forms of value.

Qualitative interviews were carried out with a group of people with dementia and their carers. The participants were members of a pre-existing group of patient advocates, facilitated by the Alzheimer's society, who represent the voices of patients and carers in research. Given the increasing success of campaigns to ensure the voice of people with dementia is represented, there are a growing number of people in the early stages of dementia - like our participants - being called upon to account for their experience, as a means of developing a politicised collective illness identity (Brown et al 2004).

Consequently our interviews have multiple meanings. They highlight the ways in which people with dementia participate in their own identity construction, performing biographical reconstruction (Carricaburu and Pierret 2008) to make sense of their lives and preserve their sense of self. As representatives of the patient voice, these interviews also show the ways in which illness narratives can produce material and symbolic value. We discuss the implications of this for qualitative research with people with dementia.

### **Experiencing Young Onset Dementia in the Family: A Qualitative Longitudinal Case Study of a 12 Year Old Granddaughter**

*Bellass, S.*  
(University of Salford)

The subjective experience of dementia in the under 65s (young onset dementia) has received greater attention in recent years, yet qualitative studies often focus on people with dementia or their primary carers, neglecting the effects of the condition on other family members (Roach et al., 2013). Notably, there is an absence of knowledge on the experience of being a granddaughter of someone living with the condition.

Drawing on qualitative data collected over a twelve month period as part of a doctoral study, this presentation will describe the experiences of a 12 year old granddaughter of a person living with Alzheimer's Disease, illuminating the evolution of her subtle and sophisticated understandings of the condition over time. Utilising an over-arching symbolic interactionist perspective, and with theoretical insights from the sociology of chronic illness and family practices (Morgan, 2011), the presentation will explore how the meanings of her grandmother's dementia are shaped by her purpose and agency, how interactional disruptions can unsettle the processes by which family relationships are reconstituted, and how she develops understandings of the acceptability of responses to family illness amongst her peers.

In addition, how she experiences the effect of the seemingly increased permeability of her grandmother's sense of self on their relationship offers a unique insight into intergenerationality in the context of young onset dementia. This presentation will contribute to current themes within sociology such as the effect of progressive illness on selves and relationships over time and the processes by which meanings of illness are socially negotiated.

### **The Significance of Age in the Experience of Breast Cancer for Women Diagnosed Under the Age of 45**

*Rees, S.*  
(University of Warwick)

Although much research has examined the experience of breast cancer, the distinctive perspectives and lives of young women have been relatively neglected. Around 20% of breast cancers are diagnosed in women under the age of 50. Qualitative, semi-structured interviews were undertaken with twenty women aged 22-43 at diagnosis. All had completed their treatment and were at least one year on from their diagnosis. The methodology was informed by social constructionist grounded theory, feminist, and intersectionality perspectives, and preliminary analysis was carried out concurrently with data collection. The research drew on theories of embodiment, biographical disruption and liminality, and gender and intersectionality, with the aim of gaining an understanding of the impact on multiple spheres of young women's lives. The effects of diagnosis and treatment resulted in profound uncertainty regarding fertility, pregnancy, and menopausal status. This, and the constraints of the treatment timescale, resulted in a perceived loss of agency over their future and life course. Gendered ideals about the body, motherhood, and femininity had significance for the young women's lives after breast cancer. Three women were diagnosed when they were pregnant, and others had very young children at diagnosis. Treatment impacted on their ability to care for their children, and it informed their experiences of early motherhood. In this paper, the distinctive ways in which age and gender, and their intersections, shaped young women's experiences and perceptions of living through and beyond breast cancer will be explored.

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### **An Exploration of the Experiences of Adults with Congenital & Early-Acquired Hemiplegia**

Neal, K.

(Royal Holloway, University of London)

Hemiplegia is a form of cerebral palsy affecting one side of the body, resulting from damage to the brain. Despite it being a non-progressive condition, physical deterioration can occur with age and as a result of imbalance, and around half of people have additional diagnoses, such as epilepsy, learning difficulties and emotional problems (HemiHelp, 2015). Research has largely focused on children with hemiplegia, and the experiences of adults following stroke in adulthood; thus there currently lies a gap in the sociological literature surrounding the experiences of adults with congenital and early-acquired hemiplegia. This research draws on literature from the fields of medical sociology and disability studies (such as debates around impairment/disability and medical/social models), on self and identity, the body, chronic illness, and stigma. Symbolic interactionism, the theoretical approach underpinning this research, is considered a suitable and relevant one since it allows exploration of the social and interactive nature of the body and identity in disability. A constructivist grounded theory (Charmaz, 2006) is used, with data collected through approximately twenty qualitative semi-structured interviews, which have ranged in length between one and five hours. This paper will explore early findings, touching on areas such as the 'visible' and 'hidden' aspects of the condition, transitions, the impact of hemiplegia on self and identity, and techniques and strategies used. The position of the researcher as an 'insider' will also be reflected upon.

### **Narratives of Traumatic Brain Injury and Self-Management Following Hospital Discharge**

Makela, P.

(University of Westminster)

Neurorehabilitation has been described as 'a world where the spotlight has commonly turned away from context, power, co-production of meanings' (Weatherhead and Todd, 2014, xi). The treatment philosophy following traumatic brain injury (TBI) focuses upon physical needs, while complex, longer-term experiences (encompassing cognitive, psychological, emotional and social effects) are not prioritised. Biomedicine rarely embraces narrative approaches, which can offer nuanced insight into experiences beyond functional outcomes, such as satisfaction with activities or engagement in personally meaningful roles.

This study explores the ways people with TBI construct stories about managing their recovery and daily life after hospital discharge, using the methodology of narrative inquiry. Through maximum variation sampling, a range of post-injury experiences are explored. Each participant was asked to select a relative or significant other to participate in the interview, allowing inclusion of others' stories, their differing concerns, needs and coping strategies.

Findings from interpretive analysis from four selected dyads will be presented, comprising particular stories of the ways in which people actively manage recovery within their own contexts. I incorporate reflection on my own role in the construction of shared meanings in undertaking narrative inquiry, on the background of my clinical work as a neurorehabilitation physician. This provides an opportunity to contrast individuals' own experiences with the 'master narrative' of healthcare services for patients after TBI. Finally, I consider the potential application of findings from narrative inquiry to development and delivery of multidisciplinary support for people and families after TBI.

### **Narrated Lives of People Affected by Acquired Brain Injury**

Brewis, C., Van Wersch, A., McNamee, A., Wilson, C.J.

(Teesside University)

Biographical disruption is a common long-term experience following acquired brain injury. It can lead to barriers in being able to fulfil roles and engage in daily activities and occupations. Biographical disruption occurs not only for the person who sustains the brain injury, but is also an experience for significant others in their lives.

This narrative study gathered participants' personal 'sense making' of life events following such biographical disruption. Extended narrative interviews were combined with a photo-elicitation technique for twelve participants. It involved discussion around the patterning of their daily activities and roles both pre and post injury.

Narrative analysis led to individualised case studies of barriers and opportunities to lives impacted by brain injury. However, synthesis of findings across cases considered the narrative form produced by the twelve accounts. This revealed that individuals drew on attributes of previous roles and careers to construct meaning and manage their lives, even when they could no longer engage with past roles and careers. Approaches to self-management post injury appeared to follow a pattern of drawing on internal schema underpinned by values, skills and meaning of previous roles and careers. This constitutes a kind of capital built up from life pre-injury and is being utilised to achieve health and wellbeing. This offers an opportunity to work with individuals whose lives are affected by acquired brain injury, by way of focusing on this 'occupational capital' to empower them to make positive change.

# Health Service Delivery

## STAFFORD 2, CAMS

**Wednesday 07 September 2016 at 12:45 - 16:45**

### **How Social Prescribing Works in Primary Care: Evidence from a Process Evaluation of the National Links Worker Programme in Scotland**

*Chng, N. R., Fitzpatrick, B., Mackenzie, M., Mercer, S., O'Donnell, S., Skivington, K., Wyke, S.*  
(University of Glasgow)

Implemented in some of the most socioeconomically deprived communities in Glasgow, the Scottish Government-funded National Links Worker Programme is an example of social prescribing initiatives proliferating across the UK. Social prescribing is where primary care professionals provide non-medical support and resources to patients who have health problems that are rooted in social circumstances. However, what work it entails, who does that work and to what purpose is not well defined.

We are evaluating this programme. This is designed as a quasi-experiment with embedded process evaluation conducted in two phases. In the current second phase, we conducted interviews and surveys with practice and Programme staff, and community organisation workers over a one-year period, and developed a comparative case study approach. We use Normalisation Process Theory to understand factors that support or hinder the routine implementation of social prescribing by practitioners in highly deprived areas.

We found that although all practices use Programme resources to provide one-to-one support for patients, improve practice capacity and staff well-being, and develop links with community organisations, practices vary in their emphasis. Some practices focus on organisational change through improved staff wellbeing, as well as practice intelligence, awareness, and signposting capabilities. Other practices work on building external relationships with community organisations. This suggests that even with a relatively well resourced and developed intervention like the Links Worker Programme, the character of primary care-based social prescribing will vary depending on the capacity, orientation, and local contexts of general practices.

### **Who is the Person in 'Person-Centred'? Challenging Therapists' Views of Person-Centred Goal-Setting Through a Self-Management Approach**

*Hardacre, N., On behalf of the LoTS2Care collaboration*  
(Bradford Institute for Health Research)

Drawing on particular cases, this paper proposes that the person-directedness associated with self-management approaches can challenge therapists' ideas of 'person-centredness'. A supported self-management intervention was developed to improve longer-term outcomes for stroke survivors. Three individuals were trained as self-management facilitators to begin piloting. This involved working with stroke survivors to problem-solve using goal-setting and action planning. One facilitator was an occupational therapist (OT) and at the start of the work her confidence in her ability to support goal-setting was based on her professional experience as an occupational therapist: 'as an OT, person-centred goal setting is my bread-and-butter'.

Contrary to her expectations, however, supporting people to 'self-manage' was challenging and actually entailed distancing herself from her professional training and experience. She reported needing to remove herself from the goal-setting process in order to fulfil her facilitator role; the goals she wanted to set for others (and would have done as an OT) were not the goals that individuals were setting for themselves. Doing this work resulted in her feeling that her OT work lacked 'person-centredness' because her ideas about someone's needs imposed on the process. This paper proposes, then, that the personhood of the patient may remain unrealised if the personhood of the therapist is unreflexively embedded in therapeutic goal-setting. However, applying principles of self-management—focusing on being led by patients, not leading them—resulted in the facilitator feeling that her occupational therapy practice had concurrently become more meaningfully person-centred. Self-management approaches, then, may benefit both intended recipients and therapists.

### **Socio-Cultural Challenges Faced in Implementing Self-Referral Physiotherapy in Primary Care- a Qualitative Study of Staff Opinions**

*Goodwin, R., Moffatt, F., Logan, P., Hendrick, P.*  
(University of Nottingham)

It is widely accepted that the NHS faces an unprecedented productivity challenge. General practice, the 'cornerstone' of the NHS is no exception, with financial pressures, increasing public demand/expectations, issues with recruitment and retention, and the imperative to secure a sustainable service for the future. Within this challenge, healthcare professionals are identified as playing a critical role, in particular, identifying opportunities for greater innovation in

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clinical delivery. One response to this has been the implementation of in-practice physiotherapy self-referral schemes. This is a potentially significant solution to the challenges faced by general practice, given the suggested burden of musculoskeletal problems. Despite the empirical support there appears to be tardiness in the implementation of such schemes in England.

This qualitative study sought to explore the socio-cultural challenges faced in implementing such a service. Specifically, it utilised a theoretical lens from the social science discipline of Science, Technology and Society, aiming to expose distributed costs and benefits; the variety of value systems underpinning the intervention, and the complementary arrangements involved in its delivery. Semi-structured interviews of general practitioners, physiotherapists and administration staff were conducted across two practices piloting a 'Physiotherapy as first point of contact service'. The data revealed several key themes: the imperative to effect a cultural change; implications for working practice/distribution of labour; identifying/valuing professional expertise; and managing risk. This work makes a valuable contribution to the understanding of changing practice in contemporary healthcare, providing insight to the professional challenges faced by a smaller allied health profession.

### **Neurorehabilitation: A Disciplined Disciplining Discipline**

*Cummins, C., Payne, D. Kayes, N.M.*  
(AUT University Auckland)

Neurorehabilitation is an encompassing health service for individuals who experience impairments as a result of a neurological injury or disease. It aims to improve functioning, reduce disability and assist the individual to achieve a desired state. To explore how clients make sense of neurorehabilitation, a poststructural approach informed by Foucault's theories of discourse and power was used to conduct a discourse analysis of text where six neurorehabilitation clients discussed their relationships with their practitioners. The analysis explored how they constructed neurorehabilitation and positioned themselves as its subjects.

Neurorehabilitation was constructed as a discipline that selected a particular type of person to be its subjects and then acted on their behaviours. As a body of knowledge with techniques to shape behaviour, the discipline functioned as a technology of normalising power internalised by its subjects to address situations where function differed from what was considered normal. The subjects were disciplined by, and disciplined themselves with the practices of the discipline to achieve desired ends.

The subjects were intertwined in a strategic power relationship that involved obligations and responsibilities. It demanded their sacrifice and commitment in return for independence and wellbeing. Viewing neurorehabilitation as a discipline reveals some of the strategies this technology uses to achieve its ends. This can assist practitioners to attend to the possibilities these strategies offer and be wary of its potential dangers.

### **Exploring the Implementation of the 'Caring for Someone with Cancer' Booklet in Community Nursing Practice: A Stake Case Study**

*Mathieson, A.*  
(University of Manchester)

The majority of people die in acute care, although most prefer to be cared for and die at home. Family carers are crucial to enabling this preference. Interventions offering practical information to prepare carers for this role are required. Luker and colleagues developed and evaluated such an intervention: 'Caring for Someone with Cancer' booklet. The booklet received positive responses from family caregivers and district nurses, but raised questions regarding how it should be implemented, suggesting further feasibility work. This study explores how the booklet has been used within a large NHS Community Trust to identify the unknown processes surrounding its implementation. An instrumental case study design (Stake: 1995) was adopted. Semi-structured interviews with key stakeholders and social network maps were used. Formal and informal observations were made, and documents collected. Sixteen community practitioners recruited across the Trust participated. Analysis using Normalization Process Theory (NPT) reveals degrees of normalization across the boroughs. The booklet has been used for different purposes, in different care settings and for different long-term conditions. The NPT construct of Collective Action help explain the work people do to enact the delivery of the booklet and barriers to its use. Restructuring of the Trust, staff morale, competing work demands, and availability of resources impacted upon its implementation. Findings suggest active implementation of the booklet requires facilitation, continued support and training. A future study, which aims to implement the booklet with community nurses and care home staff, will explore these barriers further and evaluate the use of NPT.

### **Tracing the Liverpool Care Pathway in Norwegian Healthcare**

*Melby, L.*  
(SINTEF)

The Liverpool Care Pathway (LCP) is a plan for providing systematic care for the dying patient. In Norway it was introduced locally some years ago and has spread throughout the country without any coordinated effort from the

health authorities. In England LCP was met with massive critique for creating more harm than care for the dying patient and was consequently withdrawn. In Norway, however, we see a continued spread in use.

Based on a study of palliative healthcare services, including experiences with the use of LCP, the main aim of this paper is to trace the actors in the 'LCP-landscape' and explore their divergent arguments for using – or not using - LCP. The data material includes interviews with health care workers and survey data, and was collected in 2015-2016. In the presentation the following themes will be addressed: Who are engaged in the debate surrounding LCP, and who remains silent? On what kind of rationale do the actors base their argumentation (e.g. scientific, political)? And how is the use of LCP reflected upon by the study participants who use the plan? By providing the empirical example of LCP in Norwegian healthcare, the paper aims at contributing to the understanding of how care and policy are woven together.

LCP was slightly revised and renamed 'The last days of life. Plan for relief at the end of life' in Dec. 2015 in Norway.

### **A Question of Compliance? The Sociologist in Healthcare Safety and Quality Research**

*Hope, J.*

*(University of Southampton)*

This paper critically examines the role of the sociologist within interdisciplinary healthcare safety and quality research. It uses ongoing research into the reduced frequencies of vital signs observations at night as a case study. The research involved interviews (n=17) exploring varying compliance with track and trigger protocols using a digital tool (VitalPAC). Interviewees were Nurses and Health Care Assistants from wards within a single hospital where the completion of vital signs observations on time at night (according to the protocol) varied. Eligible respondents (those using VitalPAC who volunteered through a survey) were approached to participate in face-to-face or telephone interviews, according to preference. Researching accounts of adherence to safety protocols raises complex methodological and ethical issues for sociologists. Firstly, the sociologist's role in eliciting and interpreting accounts of compliance and non-compliance within the context of wider performance surveillance. Secondly, taking account of the status of nurses' and health care assistants' explanations of noncompliance in the context of medically-led protocols and research. Finally, what it means to 'do sociology' within health service research teams whose own performance is audited via the REF's impact agenda. The critical examination of such issues throughout the research process is important in contributing to discussions about the developing field of the sociology of healthcare safety and quality. However it also has a wider significance in situating medical sociology work within debates about the nature of public and critical sociology in the current financial and political climate, both within academia and health and social care.

## **Inequalities**

### **WHITEHALL 3, CAMS**

**Wednesday 07 September 2016 at 15:40 - 16:45**

### **The Embodiment of Disadvantage: Developmental Programming and the Lifecourse**

*Kriznik, N., Kelly, M.P., Kinmonth, A. L., Burton, G.J*

*(University of Cambridge)*

This paper discusses how insights from developmental programming can illuminate sociological analysis of the inter-generational transmission of health disadvantage and reproduction of health inequalities. Developmental programming is the biological process whereby environmental factors (such as poor maternal nutrition or elevated maternal stress hormones) influence gene expression during in utero growth and beyond. Acting during vulnerable periods of development, these factors can alter the structure and function of major organ systems for the rest of the lifecourse of the fetus, infant and adult, explaining important aspects of adult morbidity and mortality.

We argue that developmental programming offers novel ways to understand how social disadvantage is embodied within our biology, how this impacts health over the lifecourse, and how these effects can be transmitted to future generations. There is clear evidence of inter-generational transmission as biological capital from grandmother through her daughter's ova to the adult health of the grandchild, which is highly significant. Subsequent social exposures can reinforce effects over generations leading to the accumulation of biologically and socially inherited disadvantage.

An integrated understanding of the reciprocal impact of the social and the biological may offer a powerful framework for guiding policies and interventions to 'tackle' health inequalities. This line of inquiry opens up the possibility of understanding biological mechanisms demonstrating the pernicious health effects of social disadvantage and the recursive nature of their manifestations across time and place. It reinforces too the importance of public health efforts directed to the health of women of child-bearing age and of young children.

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### **The 'Good', the 'Bad' and the 'Difficult': Clinical Learning and the Entrenching of Inequality**

*Sointu, E.*  
(*Smith College*)

This paper develops sociological understanding into the reproduction of inequality in medicine. To highlight the subtle, yet powerful, ways in which inequality is reproduced and entrenched, this paper analyses ideas of the 'good' and the 'bad' patient among medical students undertaking clinical rotations. 'Bad' patients question not only biomedical knowledge but also medical students' commitment to helping people. 'Good' patients engage with medical students in a manner that upholds biomedical knowledge as well as enables students to assume the role of the healer and the expert. At the same time, 'good' patients possess cultural skills that align with those of medical practitioners. This alignment is, furthermore, central to definitions of the 'good' patient. Distinctions drawn between 'good' and 'bad' patients thus both embody as well as enforce social inequality. The subtle reproduction of inequality is, however, difficult to discern because judgments about patients are entwined with emotional responses that patient encounters engender. The material is drawn from a longitudinal study into medical student experiences of clinical learning. The study entailed 68 qualitative in-depth interviews with 27 medical students undertaking clinical rotations in five medical schools in the United States.

## **Lifecourse**

### **STEELHOUSE 2, CAMS**

**Wednesday 07 September 2016 at 12:45 - 16:45**

### **Developing an Approach to Tackling Alcohol Related Harm in 15 to 17 Year Olds**

*Bonnar, K., Larsen, J.*  
(*Drinkaware*)

The role of alcohol in young people's lives in the UK is changing. The proportion of 15 year olds who drank alcohol in the last week has more than halved over the past ten years from 49% to 18%. However, there is still a disparity with the government recommendation of an alcohol-free childhood; in 2014, 69% of 15 year olds in England reported that they had consumed alcohol at least once (Fuller and Hawkins, 2015). This, along with the wide range of motivations, attitudes and beliefs about alcohol held by adolescents, means it is crucial that families, schools, charities and public health bodies alike better understand the short and long term impacts of alcohol consumption amongst teenagers. Having developed an education programme for those aged under 14 as well as a campaign targeting 18 – 24 year olds, the UK alcohol education charity Drinkaware is investigating what approach should be taken to effectively address alcohol related harm among 15 to 17 year olds.

This paper outlines findings from early scoping work aiming to better understand the profiles, influences and behaviours of UK-based 15-17 year olds in relation to alcohol and what resources and interventions are available. The paper highlights methodological challenges in researching and delivering information and interventions to this group, and it discusses the need to work in partnership across public health and charity sectors, informed by principles of co-production to deliver multifaceted approaches that meet the needs of adolescents.

### **Not Welcome if Dying? The End-Of-Life Patient and Hospital**

*Hoare, S., Barclay, S., Kelly, M.*  
(*University of Cambridge*)

Hospital admissions for patients close to the end of life are denigrated in policy as inappropriate. Hospital is considered an unsuitable place to die, and implicitly dying patients are considered unsuitable recipients for hospital care. However, nearly half of all of UK deaths occur in hospital. In this presentation I will discuss how healthcare professionals (HCP) explain this paradox using data from an interview study of HCP involved in the admission of patients who died shortly after entering hospital.

Hospital was primarily conceived by HCP as a place to receive acute care from which there was a chance of recovery. End-of-life care (EOLC) patients were thus 'unwelcome' patients unless appropriate medical need could be demonstrated. HCP also though described the role of hospital as an available place of safety. This conception was often utilised by community HCP to justify sending patients in need of care to hospital and was acknowledged by hospital staff in the context of imperfect practices and limited community resources. Interview accounts show the difficult task HCP have of navigating these contradictory conceptions when considering EOLC patients, particularly within the context of often opposing policy directions and cultural conceptions of a 'good death'. Like the multiple roles of the hospital, HCP categorisations of appropriate and inappropriate reasons for end-of-life admissions were not binary and reflect the often simultaneous roles the hospital has taken throughout history. Ultimately, EOLC patients were unwelcome but accepted for hospital care.

### **Materialising Chronic Illness Through Practices of Care: Intimacy, Gender and Endometriosis**

*Hudson, N.*

*(De Montfort University)*

Endometriosis is typically described as a common, chronic gynaecological condition, which affects between 2 and 10% women of reproductive age. Characterised by diagnostic uncertainty and a diverse and complex range of symptoms, it has been referred to as the missed disease since there is no definitive cause and average time to diagnosis in the UK is around 7 years. Whilst a small but growing body of research has focused on the lived experience of women affected by endometriosis, there has been less work considering the relational, political and material aspects of the condition. Kate Seear (2014) has recently attempted to address this omission by suggesting that endometriosis has materialised as a 'modern epidemic' through the co-constitution of a range of symbolic, political, discursive and material practices and processes.

The data on which this paper is based are drawn from a qualitative interview study of women with endometriosis and their male partners (n=44). Taking the conceptualisation of endometriosis as multiple and in a state of becoming as a starting position, the paper considers how the condition emerges through everyday, gendered practices of 'care' and 'support' enacted within heterosexual relationships. It draws inspiration from the work of Seear as well as from scholars working critically on the sociology of self-care and on health and new materialism (e.g. Fox 2015). It is argued that by examining accounts of the 'everyday' materiality and practices surrounding endometriosis, it is possible to identify ways in which the 'endometriotic subject' (Seear 2014) manifests within intimate, non-medical contexts.

### **'HIV is the Least of my Worries': Syndemic Suffering in People Living With HIV in Regional Queensland Australia**

*Fitzgerald, L., Bolsewicz, K., Gardiner, B., Mutch, A., Whittaker, A.*

*(University of Queensland)*

The increasing shift towards the biomedical in the prevention, treatment and care of HIV and normalisation of HIV as a 'chronic illness' is predicated on biomedical messages being acted upon by people living with HIV (PLHIV). However, the increasing biomedicalisation of HIV is often abstracted from the specificities and complexities of living with and negotiating HIV in everyday life.

This paper utilises Mendenhall's (2012) conceptualisation of syndemic suffering, the interactive relationship between forms of violence, social suffering and chronic disease, to examine the lived experiences of people living long term with HIV in Queensland, Australia. Through this examination the paper considers how an intertwining of long term complex health issues, social disadvantage and intersectional identities, situated within a rapidly changing policy environment, influence health and wellbeing. The paper draws on data from the Living Positive in Queensland Project: A qualitative longitudinal study of aging, place and social isolation involving in-depth interviews conducted over three time periods with 72 participants aged 35 and over, who live in rural and regional Queensland. The paper examines how PLHIV long term grapple not only with complex health issues, but also structural vulnerability and precarity arising from shifting policy contexts, the dismantling of psychosocial service provision, and cuts to funding for PLHIV services. Reflecting on the results it is apparent that policy makers and service providers must recognise that both chronic structural issues and chronic health conditions influence health seeking, access to care and health outcomes.

### **The New Normal? How Patients Narrate Recovery from Chronic Fatigue Syndrome**

*Cheshire, A., Ridge, D., Clark, L.*

*(University of Westminster)*

#### **Background**

Chronic Fatigue Syndrome (CFS) is a long-term health condition for which there are few effective treatments. Return to pre-illness health is uncommon, however, there are debates as to when a patient can be classed as 'recovered' from CFS. This paper presents a qualitative investigation exploring, from a symbolic interactionist perspective, the yet unheard views of how people with CFS conceptualise and narrate recovery.

#### **Methods**

We conducted semi-structured interviews (n=19) with CFS patients who had taken part in a Graded Exercise Therapy (GET) clinical trial. Participants were asked about perceptions and definitions of recovery from CFS, and the perceived role of GET in any recovery. Data were analysed using thematic analysis.

#### **Findings**

'Recovery' was generally not defined as a return to the "self" and life prior to CFS, which was considered unachievable or too demanding (e.g. from burn-out). Rather, 'recovery' was focused on negotiating levels of 'normality': such as regaining functionality (e.g. ability to carry out everyday tasks) and having a 'normal' reaction to physical activity (e.g. a more typical recovery time after exertion). Fatigue was also measured against normativity, including discussions of 'normal' tiredness versus 'CFS tired'. Participants constructed recovery via post-CFS narratives where normality, 'levels of wellness', an ability to listen to the body, and effective management of symptoms were advanced. Adaptations to lifestyle were made to support recovery.

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Rather than searching for a total 'cure' from CFS, participants re-work personal narratives to focus on more reachable goals, allowing some form of recovery to be articulated.

### **Untimely Diagnosis: Examining the Experience of a Diagnosis Seen as Dissonant with Chronological Age**

*Kirkpatrick, S.*  
(University of Oxford)

Following Bury's (1982) exploration of chronic illness as biographical disruption, it has been argued that it may instead be accepted as biographically anticipated 'normal illness', (Williams 2000), especially at particular life stages. Sanders, Donovan and Dieppe (2002) found that older people saw the pain and impaired mobility of osteoarthritis as a normal part of ageing, consistent with their expected biography rather than disruptive of it (even if at the same time it disrupted practical daily living). Pound et al (1998) encourage us to pay attention to 'the straightforward possibility....that chronic illness may be anticipated and experienced by some older people as normal'.

However, much of the literature has focused on examples where illness is congruent with age-related expectations, rather than situations where it is seen as dissonant with chronological age. Some conditions are typically associated with particular life phases. This may include 'childhood' infections such as chickenpox or measles; type 1 diabetes as a condition of childhood or adolescence contrasted with type 2 as a disease of late middle age; or dementia as a condition of old age. In all these cases, however, the condition may be diagnosed at a different, unexpected time of life. In this paper we use secondary analysis to explore two conditions where diagnosis seems to conflict with age-related expectations (adult onset asthma and juvenile arthritis); how this affects people's experiences; and the meanings they and others attach to it. We propose 'untimely diagnosis' as a contribution to the sociology of diagnosis.

### **Polio Monologues: Translating Ethnographic Text into Verbatim Theatre**

*Shah, S., Greer, S.*  
(University of Glasgow)

Mass vaccination programmes mean that poliomyelitis is almost a forgotten memory in the Global North. But in reality its effects continue as many people who contracted paralytic polio in childhood may develop functional deterioration (Post-Polio Syndrome or PPS) in later adulthood; mass migration and escape from violence means that it is also re-emerging in contemporary societies. Thus it is crucial for different audiences to have opportunities to engage with, and understand the life histories of polio survivors and their personal experiences of disease and disability across biographical and historical time. This paper discusses the process of using recorded delivery verbatim techniques, with disabled and non-disabled actors, to translate ethnographic research about social history of polio into a creative accessible medium for new generation audiences to learn about the hidden, often contested, histories of disability and disease that may collide with professional, medical and public discourse. Our contention is that ethnodrama can give a voice to the voiceless, and enable them to contribute to the production of new knowledge, health interventions and policy instruments that affect their lives.

## **Mental Health** **WHITEHALL 1, CAMS**

**Wednesday 07 September 2016 at 12:45 - 16:45**

**'There was nothing particular I could put my finger on. I seemed to be getting worse, but then I came out again. This just went on and on and on and on': Periods of Change and Stasis in the Lives of People with Psychosis**

*Pratt-Boyden, K.*  
(University of Oxford)

The experience and perception of time for people living with psychosis has been variously described as 'impaired', 'ruptured', 'fractured' and generally lacking coherence, which aligns with Bury's (1982) view that chronic illness disrupts a person's sense of self, identity and life course. However, the nature and the lived experience of temporality and illness for individuals with psychosis is more complex.

This paper explores the conceptualisation and embodiment of time through secondary analysis of 33 narrative interviews with people with psychosis. It focuses on the ways in which participants describe events (and 'non-events') throughout their life course and how that impacts their sense of self, their past(s), present(s) and future(s).

Participants did not always perceive periods of acute illness as disruptive. Instead, their narratives highlighted a great deal of fluctuation, particularly between perceived improvements and setbacks related to their illness. Participants

talked of 'cycles', 'ups and downs', 'journeys', 'pathways', 'slipping back', 'the wilderness years' and being 'on the road to recovery', which varied greatly according to whether they perceived their illness to be permanent or something they could recover from. They described 'turning points', but also many instances of 'nothingness' and long periods of stagnation or repetition, marked by no particular change.

These findings challenge the highly popular 'recovery' model within mental health services, as well as the stigma associated with people's ability to maintain a 'coherent narrative' throughout the life course.

### **Psychiatric Home Treatment as a Vehicle for Austerity**

*Spence, C.*

*(King's College London)*

This talk will draw on 9 months of ethnographic fieldwork among a south London Psychiatric Home Treatment Team. In doing so I will present an account of the way home treatment emerges as a vehicle of austerity measures and produces particular practices and subjectivities among patients and staff.

First, I will present an overview of the development of home treatment, drawing relevant information from its historical creation and later implementation in the UK to setup its use as a vehicle for austerity. I will then present the current practice of home treatment and the way it is shaped by austerity. In doing so, I explore how prominent issues such as the constant bed crisis, financial constraints, pressure from other services, and structural reorganisation within the trust, directly shape practice.

Following this, I will look at patient subjectivities and how they too are shaped by austerity. These subjectivities are (re)constructed by interaction with the home treatment team but can also actively challenge team practice by rejecting proffered path dependency built within the system. These subjectivities can in turn offer resistance to the practice of austerity but face steep challenges based on the emergence of particular inequalities based on class, race, gender, diagnosis, and participation in the labour force.

I will conclude by making clear the inherent contradictions in mental health care that stem from austerity and give potential patterns for resistance to austerity.

### **A Realist Evaluation of a Men's Shed: Improvements in Participant's Emotional Health and Mental Wellbeing**

*Markham, S.*

*(University of Leeds)*

Men experience more incidence of morbidity and live fewer years than women (Mahalik et al., 2007; White and Holmes, 2006; Fletcher, 1992). Suggested contributions to this include biological, psychological and sociological factors (Connell, 1995; Evans et al., 2011; Gough, 2006; Marmot et al., 2010). In terms of pragmatic contributions that influence men's health the literature points to a set of foundations in support of the concept of community based organisations where men can be supported to address health and wellbeing issues whilst affirming their masculinity (Bourdieu, 1986).

Men's Sheds have been described as community organisations that provide space for men (Golding et al., 2007). A review of empirical research conducted to evaluate the merits of Men's Sheds for the improvement of men's health and wellbeing indicates that Men's Sheds are an entity comprising of mechanisms that contribute towards positive wellbeing outcomes for men (Wilson and Cordier, 2013). The reviewed studies support further research to be undertaken to understand men's experiences of participating in community-based Men's Sheds and with Men's Sheds that have a primary health and wellbeing focus; offering non-utilitarian activities (Ormy et al., 2010; Cordier and Wilson, 2014).

Empirical research, developed through the testing of realist programme theories, has identified mechanisms that support men to experience improved emotional health and mental wellbeing. This research will contribute to the current paucity of literature investigating: what is happening within the 'black box' (Astbury and Leeuw, 2010:364) to understand the mechanisms that facilitate the mental wellbeing of men.

### **Beyond Bio-Medical Models: Conceptualisations of Mental Distress in Laminated System, 'Modes of Reflexivity' and Other Critical Realist Approaches**

*Moth, R.*

*(Liverpool Hope University)*

Mental distress is conceptualised in a number of different ways. This has found expression in the diverse range of explanatory frameworks utilised by practitioners, service users, carers and others to understand and define such experiences. There has been significant recent interest in this substantive field from critical realists. The emergent realist contributions have sought to examine, clarify and critique dominant forms of knowledge in order to develop novel theoretical understandings. The theorists involved are located in the disciplines of both sociology (Archer, 2003, 2007, 2012; Pilgrim, 2015) and social psychology (Cromby, 2005).

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The paper will begin by outlining three prominent realist frameworks: Archer's 'modes of reflexivity' in particular fractured reflexivity, Pilgrim's three-fold 'misery/madness/incorrigible egocentricity' typology, and Cromby's realist 'embodied subjectivity' approach. It will go on to introduce the 'pentimento' laminated system developed by the author in a recent empirical study of conceptualisations of mental illness/distress in UK statutory mental health services (Moth, 2014). The paper will suggest both productive alignments and tensions between these four approaches. It will conclude by outlining the potential of these contextually situated approaches to move beyond bio-medically reductive models of mental illness. It will be argued that these alternatives offer not only new ways of conceiving mental health needs but also indicate the ontological mechanisms underpinning experiences of distress and, as such, point to possibilities for the transformation of the conditions in which these needs emerge.

### **Power and Positioning in the Experience of 'Mental Disorder' Within Prison Environments**

*Shepherd, A., Shaw, J., Sanders, C.*  
(GMW Mental Health NHS Foundation Trust)

#### Background

Increasing prison populations, perceived as having high rates of 'mental disorder', have prompted the establishment of mental health teams to address clinical needs. However, relatively little recent research has focused on how people experience and respond to mental health issues within the material and organisational context of prison environments; although the classical work of authors such as Foucault and Goffman still reads as pertinent. In this paper Bourdieu's concept of field theory is drawn upon to consider power and positioning as reflected in the routine practices and interactions experienced by prisoners and staff.

#### Methods

In-depth interviews were undertaken with 16 individuals diagnosed with personality disorder. Analysis was undertaken through the combination of reflexive journal writing and a thematic approach. Two focus groups with clinical staff were conducted to explore the subject from an alternative perspective.

#### Findings

Within the presented narratives prison can be seen as a social space, or 'field', separated from the general community and within which individuals exercise social capital in a central process of identity work - with participants describing the manner in which the institutional environment constrained the expression of their distress, through varying peer and professional response, and the manner in which the physical and social environment could be altered in resistance of this.

#### Discussion

Prison environments contain high levels of personal mental distress and institutional practices both constrain, and are altered by, its expression. Recognition of aspects of this process is of both theoretical and practical importance as institutions continue to develop.

### **'Small roots have grown into big things': Reflections on Improving Health Outcomes for Offenders**

*Brown, G., Brady, G., Bos, E.*  
(Coventry University)

In this paper we present research carried out by an inter-disciplinary research team of sociologists, human geographers and criminologists. Since 2013 we have been commissioned by one private and two third sector organisations delivering prison based interventions to undertake research in three English prisons. Here, we reflect on two interventions targeted at male offenders; a horticultural intervention and a faith based prison and community programme. The paper draws on a number of commonalities captured across the programmes in relation to factors that contribute to positive outcomes for offenders. Furthermore, we also raise some of the challenges and barriers associated with delivering interventions within a prison setting. Our work identifies a myriad of ways in which offender's mental and physical health, subjective wellbeing, and 'desistance readiness' is influenced by a wide range of social, environmental and psychological factors. We outline a number of key attributes associated with the positive outcomes identified, including the creation of positive spaces for offenders, the humanisation of offender's experience, and the importance of flexible approaches to people who experience fluctuating wellbeing. We also reflect on some of the methodological opportunities and challenges encountered when researching with offenders who have multiple needs, and conducting research in a prison setting. We argue that there is much that can be learned from situating the offender's journey and experiences at the centre of knowledge production.

### **Connecting Wounds: Nonsuicidal Self-injury and the Need for a Social-interactional Perspective**

*Steggals, P.*  
(York University)

Nonsuicidal self-injury (NSSI) is typically framed as a wholly individual and private matter. Though the idea that it is a form of 'attention-seeking', a kind of social manipulation or a practice of morbid narcissism, can still be found grumbling away in public discourse, both the idea and the phrase are vehemently rejected by people who self-injure.

As such the current received wisdom describes it as a purely intrapsychic phenomenon and therefore a strictly psychological subject. However a wealth of findings, typically appearing at the edges of research questions and designs, puts this received wisdom into significant doubt and strongly suggests the need to explore NSSI from a more social-interactional perspective. Following previous research into the social context and cultural meaning of NSSI, published in the monograph *Making Sense of Self-harm* (2015, Palgrave Macmillan), this paper explores how this existing work highlights the need to examine the effect social relationships have in shaping, and in turn being shaped by, the practices and experiences of NSSI. I will argue that while the more situated approach to NSSI introduced by a growing sociological literature has been necessary and welcome it nonetheless has not gone far enough: we need an unashamedly relational and interactional perspective. The methodological and theoretical resources of sociology offer a particularly sensitive yet rigorous way to do this, allowing us to navigate between an overly individualistic psychologism and the unhelpful and inaccurate accusation of 'attention-seeking', and thus charting a way forward in developing knowledge in this area.

## Politics of Health

STEELHOUSE 3, CAMS

**Wednesday 07 September 2016 at 12:45 - 15:35**

### **Rehabilitation Policies and Governmental Strategies: The Norwegian Coordination Reform**

*Røberg, A.*  
(*Sunnaas Rehabilitation Hospital*)

This paper directs a critical gaze on policy developments for disabled and chronic ill, using the case of Norway. Inspired by the work of Norman Fairclough, it undertakes a critical discourse analysis (CDA) of the interaction between medical and socio-political discourse in two influential White Papers, submitted within a period of 10 years. The purpose is to: 1) describe how the government's political approaches appear in the texts, 2) interpret how these policies contribute to change conceptualisations of rehabilitation, and 3) discuss how expanded social perspectives redefine rehabilitation practices. As such it touches upon relevant critical medical sociological concerns.

The way medical and socio-political conceptual models are embedded in the two White Papers has revealed three orders of rehabilitation discourse: The discourse of 'reaction', the discourse of 'action', and the discourse of 'pro-action'. The analysis outlines the repositioning of rehabilitation to adhere to socio-political approaches; however, a critical question is whether an identified 'Social Turn' has some unintended consequences.

A major finding is how discursive practices enable governance by encouraging certain conduct and structuring possible actions by different people within the rehabilitation field in order to reduce health cost. Central is how current techniques of government see the individual as basic entity to which government is applied. Policies of self-conduct – or governmentality – are legitimized by associating viability of the population, coordination strategies, and welfare state sustainability.

### **Policing the Mouth at Home: Tooth Brushing and Sugar Consumption**

*Lin, Y-L., Davies, K., Callery, P.*  
(*University of Manchester*)

Children with a cleft lip and/or palate (CL/P) have poorer oral health than those without the condition. Poor oral health can affect children's quality of life particularly for those born with a CL/P, due to its implications for future treatments. This study set out to explore parents and children's experience in managing oral health at home to unravel the challenges in caring for the teeth of for children with a CL/P. Semi-structured interviews were carried out with children of age between 5 to 11 and their parents. Fifty-three per cent of those invited were interviewed including twenty-two parents and sixteen children. The principles of thematic analysis were adopted to analyse the data. Parents of children with a CL/P could be highly motivated to maintain their children's oral health but some seemed to find it challenging to enact their intentions into everyday practices. Parents and children showed awareness of the importance of brushing teeth and reducing sugar consumption in caries prevention. Tooth brushing was often more strictly enforced and described as being used to compensate when sugar was consumed. This shows that, in managing children's oral health, policing tooth brushing is than reducing sugar consumption. This might be partly due to sugar being used to bring harmony and introduce power into parent-children relationship. Furthermore, tooth brushing was described as embedded in their daily routines and therefore 'norm' is established. Sugar consumption, however, was often portrayed as occasional 'treats' and thus might be harder to regulate as deviating from the 'norm'.

## Abstracts

### **The Importance Of Media In Framing Public And Political Debates About NCDs**

*Hilton, S., Weishaar, H., Dorfman, L., Freudenberg, N., Hawkins, B., Razum, O., Smith, K.*  
(MRC/CSO Social and Public Health Sciences Unit)

For the first time in history non-communicable diseases (NCDs) now pose a greater health burden than communicable infectious diseases and the media play a crucial role in framing public and policy debates about the causes of, and solutions to, NCDs. While the literature suggests that media debates should be a key concern for those interested in understanding public health policy processes, as yet there has been only limited research into the role of the media in the development of public opinion, advocacy, and policy in this area. This paper presents the findings from a scoping review which aimed to identify gaps in current research on media representations of industries that contribute to NCD risk and how media representations might be shaping public and political opinion. We focused on media studies of three NCD debates, considering how alcohol, processed food and tobacco industries have been represented in the media. Our findings indicate that: (i) limited research that has been undertaken, 61 studies over the last 30 years, mainly dominated by tobacco studies; (ii) comparative research across industries/risk-factors is particularly lacking; and (iii) coverage tends to be dominated by two contrasting frames (market justice and social justice). We conclude by identifying future research that would provide a crucial resource for those seeking to develop a common policy agenda to reduce NCD-related harm, and enhance public health advocates' abilities to use the media to promote effective public health policy.

### **'Stem Cell Success Will Prove the Bible': The Political Economy of Faith**

*Chekar, C. K.*  
(University of Leeds)

This paper investigates how the political economy of hope is socially configured in the context of regenerative medicine in South Korea. Claims of the healing power of stem cell therapies were backed up by both a Christian bio startup, and also by evangelical church networks. RNL Bio, a Korean adult stem cell company, weaved religion extensively into its vigorous entrepreneurial endeavours. The company publicised its adherence to Christian values in various aspects of its business practices widely. But more importantly, RNL Bio claimed that their adult stem cell (ASC) research and business practices are 'Christian'; in essence, ASCs are a gift from God and that the therapeutic success of ASC will prove that the Bible is correct. Superficially, RNL Bio's aim seemed to be to benefit from the Christian market and gain recognition within evangelical church networks by associating itself with these networks and their theology. However, at a deeper level, what appears to happen is a new type of bio-entrepreneurship; what I call 'religio-scientific entrepreneurship'. I argue that parts of the stem cell industry in South Korea have used their existing religious beliefs to tap into the hopes of health and wealth that fellow believers have – the so-called 'Gospel of Prosperity' – and leverage those hopes via investment from the church networks. Because the bio-company fitted the outlook of the churches so exactly, they were able to draw on their large financial reserves, and this has enabled the as-yet unprofitable industry to maintain momentum as a lucrative business.

### **The Persuasive Power of Metaphors**

*Dimond, R.*  
(Cardiff University)

In this presentation I discuss the power of metaphorical language. I focus on mitochondria donation, a controversial novel IVF technology that was legalised in 2015 following extensive public consultations and debates. The mitochondrial debates highlight how metaphors perform work: they can communicate complex information, but they can also transform, persuade, and enhance or damage reputations.

This presentation recognises a rich history of sociological understanding of the significance of metaphor, including the body as machine or 'under attack'. The genetic imaginary focuses on essentialism: we use computer metaphors to talk about our genetic 'code' and 'decoding', genes are part of the 'book of life' or 'blueprint', and the quest to map the human genome became the 'holy grail'. Metaphors are useful as a site of sociological focus because they reveal assumptions and expectations about the normal and natural, and the fears and priorities of modern society. Mitochondrial donation, which involves genetic manipulation, has been represented as a 'slippery slope' to 'designer babies', 'crossing a line' and even likened to 'Frankenstein Science'. Novel tropes have also emerged which specifically relate to the mitochondria techniques, including conceptualising mitochondria donation as simply 'changing the battery' and a linguistic repertoire of terms relating to the mitochondria donor as a genetic parent, including 'three parent babies'. The mitochondria debates reveal ambiguities surrounding our understanding of genetic material and its social significance. They also reveal the politics of language. Some metaphors were mobilised, not to characterise the science, but to discredit particular views as reductionist or irrational.

# Professions

## STAFFORD 1, CAMS

**Wednesday 07 September 2016 at 12:45 - 16:10**

### **Surgeon Education: An Investigation into the Ontological and Ethical Dimensions of Surgical Training and Practice**

*Mahendran, A.*  
(Goldsmith's, University of London)

I pack the belly with pristine, crisp swabs. Almost as soon as I place them, the white of the swabs instantly disappears, drenched in a deep crimson hue, sodden with blood. My hands quickly and methodically move cross the four corners of the abdomen; removing soaked swabs, squeezing out a shower of sticky, scarlet juice that sloshes around in a bucket while the cell saver hoovers up each precious red cell and pumps it back to the patient. Every few seconds I glance up at the rising tide of blood; I don't think I know yet that we have transitioned to the inevitable. I keep going—this is not what I'm here to do, I didn't come to watch a man exsanguinate to death. Suddenly, the world of the operating theatre; a place of good, success and heroics becomes a destination of failure, despair and death. Two worlds. I continue to 'pack and squeeze'; I choose to inhabit the land between—I'm not done. Yet.

This excerpt from my training journal forms one of three data sources in researching the ontological and ethical dimensions of surgical training and practice. At its core is a speechlessness of practice, as experienced in acute and contingent surgical environments. It characterises the 'thisness' of surgical training: an 'affective dimension' (Massumi, Whitehead, Simondon) which exceeds an emotional awakening to practice. It entails a response to a clinical encounter, the way in which this event presents itself and how it is sensed and interpreted (Badiou, Lacan).

### **Critical Care Nurses' Professional Identity: Multiple Processes of Difference**

*Belle, M-J.*  
(University of Tasmania)

Despite sociological contestation of nursing's professional status, nursing's professional identity is a topic of considerable interest as researchers attempt to explain and overcome its ambiguity. While the concepts of boundaries and boundary work have contributed to understandings of professional identity between different professions, application within professions has been the exemption, rather than the rule. This paper explores identity processes across multidimensional boundaries of difference that inform professional identity at the intra-professional level. Thus it furthers empirical knowledge of intra-professional boundary work and professional identity, and their expression within nursing.

I draw on data from an Australian ethnographic study that focuses on how Critical Care Nurses (CCNs) construct professional identity in their work environment. Data were generated from 92 hours participant observation and 8 semi-structured in-depth interviews of 13 Critical Care Nurses working in a single, regionally located Intensive Care Unit over a 5 month period. Data were subjected to thematic analysis informed by Charmaz's principles of constructivist grounded theory.

Professional identity is constructed through intra-professional boundary work by which CCNs engage in relational processes of similarity and difference with other nurses, rather than other health professionals. These identity processes acknowledge difference with reference to multiple dimensions including spatiality, temporality, gender and ideology. I argue that this intra-professional boundary work offers some explanation of the ambiguity of nursing's professional identity, and conclude that application of boundary work at the intra-professional level extends our knowledge on professional identity of health professions, and within the profession of nursing specifically.

### **'The Business End': Neoliberal Reforms and Resistance in Community Mental Health Services in England**

*Moth, R.*  
(Liverpool Hope University)

Contemporary mental health policy for statutory services in England promotes neoliberal restructuring of provision via new payments systems and personalisation. Based on findings from twelve months' ethnographic fieldwork within one community mental health team (CMHT), this paper examines the effects of this reform agenda on multi-disciplinary professional practice and conceptualisations of mental distress, and identifies emergent forms of resistance.

The paper begins with an account of the reconfiguration of welfare labour processes in statutory mental health practice utilising the notion of 'strenuous welfarism' (Mooney and Law, 2007). This describes managerialist strategies to transform the tacit knowledge of professionals into codified forms subject to audit and control. While this organisational context facilitates the intensification of mental health work it also generates performative tensions. Implications of these will be considered including tendencies towards refuge in/reduction to core activities, and a defence of ethical professionalism.

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In the CMHT studied, increasingly prominent aspects of competition disrupted attempts by mental health practitioners to sustain supportive and mutual structures and relationships. Organisational processes tended to recast service users as individual consumers 'responsibilised' to manage their own risk, or subject to increasingly coercive measures when perceived to have failed to do so. As a consequence biomedical orientations were remobilised in practice in spite of a rhetorical shift in policy and professional discourse towards recovery and social inclusion. However these developments generated a variety of forms of resistance from practitioners (and service users), and the paper will conclude by identifying examples of these at micro and meso levels.

### **Alternative Futures: Professionalization Strategies in Academic Complementary Medicine, and the Relationship to the Wider Profession**

*Brosnan, C.*  
(University of Newcastle)

The last few decades have witnessed the rapid professionalization of several types of complementary and alternative medicine (CAM), including, in some countries, their move from college- to university-based education. Despite these gains, the most established CAM professions still face challenges to their legitimacy, recently illustrated by scientist-led campaigns to remove CAM degrees from universities in the UK and Australia. Against this backdrop, this paper explores the professionalization strategies pursued within the university by CAM academics - a group that has so far received little sociological attention. Data come from interviews with 47 academics in university departments of Chinese medicine, chiropractic and osteopathy in Australia and the UK. The academics' perspectives are compared with those of key members of CAM professional bodies, drawing on a further 14 interviews in the two countries. Gieryn's notion of boundary-work and Bourdieu's concepts of field and capital are drawn on to interpret the results. Findings show that key professionalization strategies among the academics include discursive efforts to redefine their professions as 'allied health' rather than 'CAM', and to distinguish themselves from the 'fringe' elements within their professions. Another related strategy is to increase research in their respective fields. However, various obstacles hinder the academics in these goals, including a lack of support from some elements of the professions themselves. The paper demonstrates not only that professionalization is an ongoing process, but that strategies play out differently and are contested across the various sectors of a given profession, particularly between the academic and practitioner fields.

### **Understanding the Experience of Health and Justice Workers Responding to Sudden, Unexpected Child Death in the Home – An Interdisciplinary Review of the Literature**

*Marrable, T., Turner, D.*  
(University of Sussex)

Sudden, unexpected child death in the home is an event which reaches to the centre of concerns about multi-professional practices, requiring professionals from health, justice services, and social care to balance 'systematic investigation' of potential wrong-doing with 'sensitive support' for the family (Sidebotham and Fleming 2007). In the midst of this, professionals need to deal with their own fear and distress with what has been described as the 'most shocking and devastating event' professionals may face (Simons, 2004, cited in Dent & Stewart, 2004, p. x). The 'Rapid Response' after a child's death includes forensic investigation from police, health, and social care professionals, followed by a series of multi-agency meetings leading to a Child Death Review (HM Government, 2013). Although the needs of bereaved parents and other family members are meant to be respected within this process, in a recent study (Turner 2014) families described professionals whose own reactions to the child's death left them unable to cope, thus leaving the families to deal with the aftermath largely unsupported.

This paper provides the findings from an interdisciplinary, rigorous literature review which explored the substantive and theoretical evidence within the literature about these 'rapid response' professionals. It seeks to understand this difficult encounter from a perspective of professional 'emotional labour', looking more closely at the relation between emergency health services and the need for forensic examination from justice services. In doing so it illuminates the need for support and training which holds the needs of both worker and family in mind.

### **New Competences in Health Professionals' Practices Related to Brain Injured Patients' Transfer Positions Between Acute, Semi Acute and Stable Phase. An Inequality Perspective**

*Højbjerg, K.*  
(Aalborg University Copenhagen)

The Nordic welfare state, institutions, professions, patients and knowledge are under constant transformation. Health care systems are highly differentiated and specialized and patients cross several sectors and institutions to get the most 'adequate' rehabilitations process. Economic and administrative systems, manuals, guides, codes (DRG) and classification systems (ICF) tend to standardise the health care, and at the same time we know that patients and their relatives bring in different types of capital when starting out for recovery. We also know that in spite of all good

intensions inequality of health is a fact which might threaten the support to the Nordic welfare model where most health care is tax financed. The rehabilitation field within brain injured offers a critical window to study how professionals manage to compensate for the amount and compositions of capital among both more and less privileged brain injured and their relatives in transfer positions? The sociology of Bourdieu and Abbott's theory of system of professions are used as analytical framework. The paper presents preliminary analysis of data from ethnographic field studies indicating that different positions among the health- and social professionals seem to develop new exorbitant practices to align patients to the system. These new competences have different functions and they are not all attractive when it comes to the professionals' desired jurisdictions.

## **STS and Medicine**

### **BYNG KENDRICK - G11, MAIN BUILDING**

**Wednesday 07 September 2016 at 12:45 - 16:45**

#### **'Are we just giving patients more years of anxiety?' Time, Futures and Expectations and an Early Diagnosis of Alzheimer's Disease**

*Swallow, J.*  
(University of Leeds)

Efforts to diagnose Alzheimer's disease (AD) in its earliest stages dominates scientific research and healthcare policy in the UK. Focus on early diagnosis has led to the development of biomarker technologies in scientific research, and the development of initiatives including the National Dementia Commissioning for Quality and Innovation (CQUIN) Framework in healthcare policy. The CQUIN aims to increase and therefore govern early diagnosis rates for AD by screening individuals for cognitive decline in the hospital setting. It is anticipated that early diagnosis will maximisetreatment options and enable patients to 'prepare for their future' in terms of care. Drawing on qualitative ethnographic data taken from memory clinics in the UK, this paper examines the extent to which the discourse of hope embedded in early diagnosis as governed in initiatives such as the CQUIN, affects the construction of a future with AD in the present. Developing the analytical standpoint of the sociology of expectations (Michael 2000), this paper shows how the kinds of hopeful futures rhetorically enacted by the CQUIN and early diagnosis, downplays the role the CQUIN has in constituting particular expectations about a future with AD. Early diagnosis produces uncertainty for patients as to what the future might bring, and for professionals in terms of treatment options and care. Examining the promissory claims of the CQUIN through an STS lens, casts light on the expectations, anticipations and anxieties the future of an ageing population with AD produces.

#### **A Pilot Study of the Impact of Commissioning for Quality Improvement (CQUIN) on Organisational Culture**

*Corbett, K.*  
(Middlesex University)

'CQUIN' is a British health service 'Pay for Performance' framework (P4P) whereby health commissioners proportionately reward health service providers upon their achievement (or not) of quality improvement targets. This pilot study sampled one provider so as to describe both the complexity of achieving alignment with commissioner intentions via the internal networks of people/technologies and the manner in which the enactment of this alignment variously occurs across the provider to impact on the organisational culture. Aspects of Schein's model of organisational culture and Latour's Actor Network Theory (ANT) are used to understand the local enactment and translation of commissioning intentions as they are operationalised through organisational systems variably composed of multiple and heterogeneous chains of designated personnel and software. This presentation will report the findings from data analysis of two types of qualitative data: on-site field observations from shadowing actors operationalising P4P/CQUIN and semi-structured interviews with those actors reflecting on their operationalising processes. ANT is used to conceptualise the effects on organisational culture of the processes and/or mechanisms whereby intention is translated into action and the factors facilitating and /or impeding those processes of translation and enactment. The presentation will conclude by discussing this use of ANT for understanding today's health service organisational culture.

#### **Technology Adoption as a Socio-Material Process: The Case of New Technology in Healthcare**

*Sanchez-Vazquez, A.*  
(Anglia Ruskin University)

The adoption of new technology in healthcare settings involves complex non-linear relationships between the different organisational groups and new and existing technologies. These relationships must be balanced and stabilised if the

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technology is to be successfully adopted and diffused into standard every-day working practice. Sociomateriality can provide a powerful lens through which to view these complex and dynamic relationships. Given the very limited success of ICT initiatives in the NHS to date, and considerable interest from policy makers promoting new ICT across the NHS, we believe novel approaches to technology adoption are warranted.

A sociomaterial lens can highlight the important relationships between workers, the organisation and the technology being adopted in such a way as to highlight critical factors in success and failure. In particular, a socio-material approach highlights the inevitable tensions between the often competing social and technical elements comprising the organisation.

In this research, data were collected from clinicians, NHS support staff and senior managers via in-depth interviews, and extended periods of non-participant embedded observation.

Our findings show how different views of the value and benefits of technology in relation to existing practices and worldviews, give rise to an uneven implementation that prevents technology achieving its full potential.

### **Personal, to Whom? Careers, Custodianship and Control in Biomedical Big-Data**

*Atkinson, S.*

*(University of Cambridge)*

In the context of emerging global political, economic, industry and market pressures, biomedical researchers are under intensifying pressure to collaborate in large-scale scientific endeavours. Big-data is seen by many to have huge potential to identify predicative and experimental research solutions to complex health conditions, such as dementias and neurodegenerative diseases. In the UK, longitudinal studies, with in-depth data and close participant relations are viewed as core sites for harnessing this potential. Enrolling cohort studies and their participants into new kinds of collaborative relations re-personalises many of the social and ethical issues around big-data collaborations for biomedicine. However, the re-personalisation of big-data is important not to understand the interests of cohort participants, but also for the groups and individuals responsible for such studies. The construction of collaborative infrastructures illustrate a critical tension between values of collectivisation and independence, collaboration and autonomy which are used to characterise the 'good' in scientific practice. Based on a two year embedded ethnography conducted in a large-scale dementia collaboration, I examine how key actors in cohort studies think and talk about data. Drawing on Traweek (1992) and Strathern (2011) this necessitates a return to the lives, experiences, relations and investments of those who build, manage and shape cohort studies. Developing our understanding of how researchers conceptualise cohort studies and their data, presents a valuable insight into issues of ownership, control and responsibility around big-data in contemporary bioscience.

### **From People with Dementia to People with Data: Clinical Labour in Alzheimer's Disease Research**

*Milne, R.*

*(University of Cambridge)*

A 'paradigm shift' (EMA, 2016) has occurred in Alzheimer's disease, as research has moved to recognise a longer disease continuum and to identify and intervene at earlier and earlier stages. Rather than focussing on 'people with dementia', identified symptomatically in the clinic, the interest is increasingly on people with the earliest form of disease, or those without any overt symptoms at all. Research focusses on identifying the biomarkers that characterise the disease continuum.

At the heart of this work are 'big data' research structures which draw together clinical and research data. This paper explores the role of data in Alzheimer's disease research, drawing on research conducted with cohort participants and researchers. I suggest that discussions of biomedical data have considered them as moving in linear tracks, from the patient or participant, to the clinician or researcher and outwards into the world. Drawing on work with cohorts, and with public-private collaborations in Alzheimer's disease I argue that in the context of Alzheimer's disease, the value of data increasingly resides in their ability to re-attach to the bodies whence they came.

I suggest that this return to the data subject represents a critical stage in the realisation of biovalue, and that considering the labour involved in the production and reproduction of data opens the door for alternative forms of governance and avenues of ethical action that consider involvement in data infrastructures as an ongoing project on the part of both data subjects and data collectors, rather than punctuated series of encounters.

### **Care Bundles and Checklists - Technology-In-Practice and the Professions**

*Overton, C.*

*(University of Nottingham)*

Many quality improvement initiatives hinge on introducing novel material and symbolic artefacts into established social practices and forms of social organisation, often in the premise of bringing about behavioral or cultural change. Drawing from the field of Science and Technology Studies, contemporary sociology embraces a dynamic way of analysing medical technologies. The central tenant to technology-in-practice is the assumption that artefacts have a generative power, arising from the inter-relationship of the artefact and its users in action.

Drawing on debates in technology-in-practice and the sociology of professions, I critically examine how the artefacts of quality improvement are implemented into secondary care. Using a qualitative case study and ethnographic methods within two NHS Trusts, the study explores the implementation of artefacts associated with the sepsis care bundle and pressure ulcer prevention checklists.

Preliminary analysis of the early qualitative data - eight interviews and 60 hours of observations - highlights (i) the artefacts embody differing representations to healthcare workers vertically and horizontally across professional boundaries; (ii) the level of experience of the healthcare worker influences how the tool determines behaviour. This research contributes to theorising the operation of such technology, as it intersects with the professions within existing socio-technical arrangements.

### **Using Strong Structuration Theory to Understand the Implementation and Adoption of a Medication Safety Information Technology Intervention in Primary Care: A Qualitative Case Study**

*Jeffries, M., Phipps, D.L., Howard, R., Avery A., Rodgers, S., Ascroft, D.M.*  
(University of Manchester)

Healthcare information technology systems can assist general practitioners and pharmacists with medication safety activities. However the implementation of such technology in primary care, where most prescribing occurs, has been under-researched. Strong structuration theory argues that technology usage is a product of a recursive relationship between social structures, technology and human agency. We used strong structuration theory to examine the implementation and adoption of a new electronic medicines optimisation system which allows healthcare practitioners and patients access to real time patient data including prescribed medications and test results.

Six semi-structured interviews and four focus groups were conducted with eighteen participants purposively sampled from a range of stakeholder groups - general practitioners, pharmacists patients and general practice managers - from a clinical commissioning group in the South of England that was an early adopter of the system.

In response to external infrastructures, such as national policy, healthcare professionals were motivated to use the system for information gathering relating to medication usage and safety. GPs and practice managers perceived the system as requiring technical knowledge. Interactions between GP staff, other healthcare professionals and patients involved role allocation or collective use which determined how the system was used.

Strong structuration theory was found to be useful for studying the implementation and adoption of a system for medicines optimisation in primary care. Information technology interventions for medicines optimisation in primary care might consider the importance of the dynamic blend of the contextual background, the dispositions of users and the material properties of the technology.

## **Theory**

### **WHITEHALL 2, CAMS**

**Wednesday 07 September 2016 at 13:55 - 16:10**

### **Of Sheep, Shepherds and Sheepdogs? The Dynamics of Pastoral Power in the Government of Patient Medicine-Use**

*Waring, J.*  
(University of Nottingham)

This paper re-visits Foucault's concept of 'pastoral power' as a mechanism of government within the social organisation of healthcare. The concept has an important role in Foucault's genealogy of governmentality, where pastors operate at the nexus of discipline and subjectification through 'shepherding' the behaviours of the 'flock'. In this paper we consider the inter-connected forms of pastoral power introduced through policies to promote patient adherence to medicine use. Specifically, we describe a three-way exchange between prescribing GP, dispensing pharmacist and (non) adherent patient. On one level, policy creates a relational system that might be interpreted as involving an overseeing shepherd (GP), a disciplining sheepdog (pharmacist) and docile patient (sheep). We find, however, that in this context pastoral power is more dynamic. Although operating within an overarching system, pastoral relationships can illustrate a 'schism' or competition to shape patient behaviours based upon claims to expertise and salvation. Pastors were also active in surveying and reflexively monitoring one another, as well as the patient, through identifying areas of inconsistent or unsafe practice. Patients were also active in resisting pastoral influence, through drawing upon alternate belief systems to justify non-adherence, and through exposing the inconsistencies between pastors. Significantly, this recursively influenced pastors as they sought to respond to both patient resistance and professional competition. The paper reveals a form of inter-subjectification, where the government of pastors and subjects is located within complex networks of relations. It also restates the importance of agency with Foucault's ideas and highlights a problematic of governmentality.

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### **Alienation, Health and Wellbeing**

*Yuill, C.*

*(Robert Gordon University)*

Despite all its promise to link various aspects of reality, alienation theory has been underused in medical sociology, especially in relation to workplace health. Drawing on research involving qualitative interviews with 16 social workers concerning their health and wellbeing in the workplace, an example is made of how alienation theory can be operationalized. The empirical findings provide two insights.

The first insight indicates how alienation theory can be used in sociological research. Processes such as seeking out internal relations and the use of abductive reasoning are highlighted here, and how we can model the pathways by which alienation negatively impacts on health and impairs wellbeing. The model focuses on the contradictions and interplay of objective structural and subjective resistances that attempt to deal with the contradictions of modern work. Those attempts to resist can fail, resulting in a negative dialectic in the health and wellbeing of the worker.

The second insight is into the empirical experiences of a fraction of workers experiencing the logics of neoliberalism. Their former professional status has been considerably reordered and their impulse to engage in meaningful work is negated by the estranging demands of bureaucracy. What emerges is a snapshot of the demands made the bodies and minds of workers in the new workplace, as well as the strategies they develop to offset those demands as much as they can.

### **'Liquid' or 'solid' or Both– How to Conceptualize Professional Work in Contemporary Healthcare Delivery?**

*Olsvold, N.*

*(Diakonova University College)*

In what Zygmunt Bauman (2003) calls the age of 'solid modernity' common problems related to the projects of the modern world such as coordination, trust and risk gave rise to practices of supervision. The goal of good supervision was to cut down on the choices of those being supervised. There was a right way of acting and behaving that would

ensure stability and eventually reduce the need for change. In 'liquid modernity' things are different according to Bauman, as we now live in a state of constant change with no expectation of ever arriving at a state of perfection or even of constructing durable structures. Flexibility and life-long learning are the current mantras and responsibility for ever-changing projects is no longer assigned to central authority but to each and every one of us.

Applying these concepts to professional work in contemporary health care it is possible to address some of the paradoxes and contradictions that characterize present day service delivery. Using examples from a qualitative case study of the implementation of a change in the practice of high technology care in a cardiothoracic ICU, I discuss how health professionals struggle with the interplay between the limited options and clear division of responsibility offered by professionalism in 'solid modernity', and the multiple responsibilities brought on by the blurred professional boundaries and increasing systemic contradictions that characterize healthcare in 'liquid modernity'.

### **Imagining Health(Care) in the Digital Society: A Multi-Site Case Study of the Introduction of Mhealth Technologies for HIV Care**

*Marent, B., Henwood, F., Darking, M.*

*(University of Brighton)*

In his opus magnum 'Theory of Society', Niklas Luhmann followed the hypothesis that the introduction of the computer and Internet technologies as new communication media will bring about fundamental changes within the societal structure and culture. Currently, within medical sociology, the various ways in which digital technologies affect experiences (of health and illness), practices (of self-care and treatment) and structures (of care provision) are widely investigated.

Contributing to these research fields, this 5-year study investigates the development and implementation of a mobile health (mHealth) platform to enable self-management of HIV in patients in five clinical sites across the European Union. The platform will provide users with Smartphone applications which interfaces securely with medical data and facilitates remote access to healthcare providers. In the first study year, 10 group discussions and 20 interviews with patients have been carried out to explore imaginations and concerns regarding mHealth technologies prior to implementation.

Data analysis (based on grounded theory) revealed several tensions (certainty/uncertainty, taking control/loss of control, autonomy/dependency, and closeness/displacement) that patients imagine when faced with digital health technologies. Discussing these results from the background of Luhmann's theory, we argue the emergence of a new type of patient. The 'next patient' adopts a culture form of 'operational control' in order to deal with the amount of data that is instantaneously available through mHealth technologies. This involves looking what happens on a Smartphone screen (rather than asking: 'Why?'), accessing no more information than is needed and employing short-term illness management strategies shaped by digital devices.

# Citizenship and Health

## STAFFORD 1, CAMS

Thursday 08 September 2016 at 09:00 - 11:50

### **Social Support for Health - Caring Kindness or Pastoral Power?**

*Hiscock, J.*  
(Bangor University)

Social support for health is commonly viewed in both the academic literature and everyday moral norms as a universal good. However, using Foucault's concept of 'pastoral power' I suggest a very different way of viewing this.

This will be based on findings from a qualitative study about interactions about health amongst friends and informal social connections. Purposive sampling included: gender, age, condition, severity of condition, deprivation and urban/rural. Data were gathered through qualitative interviews. Case study analysis was conducted to inform the development of codes and to identify broad themes which could not be segmented into codes. Transcripts were coded, organised using NVivo and interpreted, guided by the research questions and research team discussion.

The study revealed an interesting tension between kindness and surveillance in health related support for social network members. Study participants gave examples of advice giving, observing, monitoring and 'checking up' on others in their social networks which could be seen on the one hand as kindly and caring and on the other hand as monitoring, surveillance or the construction of power.

This paper will use Foucault's notion of 'pastoral power' to develop an analysis of these tensions and to suggest that the iconic notion of 'helping the sick' is loaded with moral authority building and can be seen as a form of power and control.

### **Prisoner Health and Well-Being, on Becoming a Citizen and the Role of 'Commensality' as Part of a Desistance Journey that Develops Social and Cultural Capital**

*Parsons, J.*  
(Plymouth University)

This paper presents findings from an SHI Mildred Blaxter post-doctoral fellowship award that examined 'commensality' (eating together around a table) as a tool for health, well-being, social inclusion and community resilience at a rural land-based prisoner resettlement scheme, that offers support and training to men released every day from prison on temporary license (ROTL) and former prisoners, referred to as 'trainees'. The ethnographic fieldwork entailed six months of participant observation of lunchtimes and associated 'food' activities, twenty-one in-depth interviews and a 'photo-dialogue' focus group on the topic of 'food' with staff and trainees. The research suggests that 'commensality' is beneficial for both trainees and the wider community; it breaks down barriers and challenges widely held stereotypical beliefs about prisoners. It exposes trainees to the symbolic, social and cultural capital associated with commensality and contributes to developing a pro-social identity in a 'family' oriented environment. It has been well documented how prisoners are constantly under scrutiny and on guard in prison (Crewe and Bennett 2012) due to the intense regulation of everyday life that is typical of a 'total institution' Goffman (1968). Contemporary desistance theories suggest that successful reparation is social as well as individual, and the change in status from prisoner to citizen has to be acknowledged and reflected back. Commensality is therefore beneficial as it helps to expose trainees to social and cultural norms and values. Importantly it highlights how 'cultural' as well as social capital is significant in an individual's journey towards successful reintegration in to the community.

### **Plastic Citizenship, Aesthetic Belonging: Plastic Surgery and Corporeal Constructions of Nationalism in Brazil**

*Bonyeme, L.*  
(University of Toronto)

This paper seeks to add to recent inter-disciplinary efforts in investigating how cosmetic interventions play a key role in conferring citizenship rights and in recognizing the productive place of bodies within ideas of the social and the nation. I look at the specific example of the cosmetic surgery industry in Brazil. Aesthetic surgeries in Brazil have been effectively 'democratized,' with public-funded hospitals now offering free or low-cost operations to the urban poor. Cosmetic enhancement, derived from a modern national discourse of a Brazilian metaracial bio-type, is seen as a potential source of social mobility for working class women. In addition, conceptions of citizenship have shifted along the lines of bodily consumption and, through it, access to market participation. Pooling from previous theoretical work on bio-, medical, and cultural citizenships, I posit the term plastic citizenship to describe the ways in which the surgical (meta-) racial body has become the space on which a Brazilian national sense of belonging is negotiated. Further,

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using the concepts of corporeal nationalism and politics of belonging, I explore how the Brazilian onus of beautification and racial mixing creates a sense of aesthetic belonging. I conclude by briefly pondering how this discussion can be thought about in relation to the trans-national movement of (female) bodies. Particularly, how foreign racialized bodies would inter- or counter-act with this national discourse. Future research should focus on unveiling 'relational webs' and 'paradoxes of care' in the management of national and foreign bodies – specifically in relation to bodily modification practices.

### **Surgery Abroad: Self-managed Cross-border - Healthcare Processes in the European Union**

*Nikolov, P.*  
(Stockholm University)

European integration contests the embedded relationship between social citizenship and nation-state borders. EU member-states have recently enforced cross-border healthcare mobility rights. National law in Sweden allows its citizens to apply for reimbursements for planned healthcare in any other EU-state. I approach cross-border healthcare as multiple relations between Swedish citizens and medical practice fields in Sweden and other EU-countries.

Modern healthcare depends on a range of processes interlinking health/medical professionals in primary and specialised care. Such processes are typically coordinated by the public healthcare system in European welfare-states. Cross-border healthcare in contrast not only demands individually accessing healthcare abroad, but in many cases entails self-managing treatments abroad with continued rehabilitation in the home locality. I examine such citizen-managed processes involving surgery for complex musculoskeletal disorders or bariatric surgery. This is primarily examined through in-depth interviews with Swedish citizens with such surgery experiences as well as via interviews with cross-border healthcare practitioners - such as health/medical professionals, civil society and company leaders.

Patient choice research demonstrates that welfare-state citizens prefer accessing healthcare in their home locality. My research reveals that cross-border healthcare processes typically entail citizens firstly accessing healthcare for diagnostics or treatment locally in Sweden and finally reentering the Swedish healthcare system for rehabilitation after their surgery abroad. Cross-border healthcare is not only linked to market activities, but it is as well facilitated by non-profit patient-advocacy organizations and other less formal citizen associations. My intention is to distinguish cross-border healthcare processes involving such variable multi-local trajectories from a citizen perspective.

### **Some (Contradictory) Health Implications of Changes in Car-Based Mobility for Young Adults in the UK**

*Green, J., Christie, N., Prior, L., Garnett, E., Steinbach, R.*  
(London School of Hygiene and Tropical Medicine)

Globalising forces potentially generate hyper-mobility for elites, whilst degrading localities. For young adults living outside metropolitan centres, the jobs, opportunities and social life necessary for health now lie at increasing distance from the home. Accessing these therefore often requires access to a private car; for many, this can be a challenge. This paper draws on data from small group interviews about everyday mobility with 16-21 year olds and parents in Northern Ireland, England and Wales to reflect on the health implications of changing patterns of mobility in era of austerity. Young adults' desires to drive were largely mundane - to access work and apprenticeships, rather than relating to independence or status - and they emphasised the responsibilities of driving (to keep themselves and others safe, to earn sufficient to keep a car) not its freedoms. The tensions between desires for mobility, pragmatic constraints and communal responses generated both health promoting and health risking practices at the level of everyday mobility, and contradictory implications for public health at a more structural level. For instance, the necessities for lift-sharing fostered social integration, but also obligations to accept lifts from 'risky' drivers. At a structural level, private cars had apparently lost their former allure as the ultimate iconic consumer item, promising perhaps an end to an unhealthy 'regime of automobility' – but in rural areas, the absence of alternatives rendered the 'local' isolating and limiting for young adults.

## **Experiences of Health and Illness** **G63, MAIN BUILDING**

**Thursday 08 September 2016 at 09:35 - 12:25**

**How Taking Statins Becomes 'The Right Thing to Do': Situating 'Deciding' Within a Web of Everyday Practices**

*Polak, L.*  
(London School of Hygiene and Tropical Medicine)

This paper is about deciding to take regular preventive medication. In research about medication practices, 'deciding' is generally elided from the picture, implicitly situated offstage and conceptualised as a cognitive process which informs the material practices involved in pill-taking. In research focused on decision-making, and in accounts of non-adherence or resistance to medication, material practices are relegated to subsidiary roles. The gap between these two approaches can be bridged by adopting a broader definition of 'deciding' to take regular medication, reconceptualising it as the process of constructing a presentable explanation for taking it. This process involves multiple interactions with people, things, and discourses which come together to make daily medication-taking ordinary or 'thinkable'. The paper draws on data from interviews in south-east England with 34 participants who have been offered statins; to study the way that people come to take regular medication, analysis centres on 19 participants who are currently taking statins, using elements of a grounded theory approach. Statins provide a useful case study, as they are prescribed purely for prevention, and are taken while people feel well, allowing the processes which constitute 'deciding' about medication to be explored in a setting where pain and illness are not rationales for action. Rather than balancing benefits against harms, as some of those who have declined statins do, those taking statins present it as 'the right thing to do'. The interaction between 'deciding' and 'doing' is portrayed as two-way: everyday medication routines shape decisions as well as being informed by them.

### **Positively Different: Contemporary Understandings of HIV**

*Walker, L., White, C.*  
(University of Hull)

The experience of living with HIV has changed significantly in the past 20 years. This is largely a result of contemporary western medicine, which now offers effective biomedical methods of HIV treatment and prevention. HIV is now widely considered to be a chronic, treatable, long-term 'disease like any other'; consequently it has been argued that HIV has been 'normalised'. Drawing on qualitative data, this paper explores the question: is it different now? It explores the ways in which the subjective experience of being diagnosed and living with HIV has (or has not) changed – is it experienced as 'normalised condition' and what are the implications of this for people living with HIV? This research was conducted with younger people (age 18-35) as their experience of diagnosis, access to information, education and societal messages are significantly different from older HIV positive adults. The findings of this research are drawn largely from online research, supplemented by in-depth interviews. Respondents (aged 18-15; HIV positive; who have received their diagnosis in the past 5 years, living in the UK) were invited to participate in an online research blog and questionnaire. The initial findings of the data identify that living with HIV is a highly ambiguous experience where its 'normative' status battles with the ongoing experience of fear, shame and stigmatisation. We suggest that the drive to 'normalcy' may ironically constitute a further mechanism to generate silence.

### **Type 1 Diabetes in Work Life: A Matter of Containment?**

*Møller Hansen, U., Tjørnhøj-Thomsen, T., Cleal, B., Willaing, I.*  
(Steno Diabetes Center)

As the working population with type 1 diabetes spends one third of their time at work, diabetes management in work life significantly impacts on the overall care and quality of life with diabetes. So far, however, little attention has been paid to the challenges of balancing the demands of routinized diabetes management with the demands of work life. In this study illness behaviour in work life is articulated using the theoretical concept of containment, as coined by the sociologist Alonzo (1979). The qualitative study rests on in-depth interviews with 40 people with type 1 diabetes from Denmark. By evoking sociological theory we mobilize an analytical strategy that enables us to explore the interplay between type 1 diabetes and work life in a situational perspective. The interviews indicate that containment of type 1 diabetes calls for continuous day-to-day negotiations in the context of work life in order for people with type 1 diabetes to stretch available resources to appear as 'good workers' while sustaining themselves as 'good patients'. As a result of an abductive analysis a local theory of containment of type 1 diabetes in work life is developed. The theory suggests that containment processes unfold at two levels: Daily containment actions refer to the practical efforts of managing the daily flux of type 1 diabetes while containment logics refer to a strategic level governing the daily and future containment actions.

### **Childhood Epilepsy: Care Experiences and Involvement**

*Black, R., Harden, J., Pickersgill, M., Chin, R.*  
(University of Edinburgh)

A diagnosis of childhood epilepsy holds a variety of implications for the child and their family beyond epileptic seizures, including intricate and multidimensional care arrangements. Despite growing recognition of the importance of listening to and consulting with children regarding their healthcare, children's accounts regarding their epilepsy and their involvement in the associated care is under-examined.

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In this paper findings from my PhD research will be discussed, drawing on data gathered from twenty-three Scottish families. The study explores the everyday experiences of children with epilepsy and examines their involvement in their own healthcare management in formal and informal contexts. Children with a diagnosis of active epilepsy and their parent(s) were interviewed separately on two occasions. Observations of a clinical consultation were conducted between the two interviews and guided the second interview's focus on a children's involvement in care in formal healthcare settings.

Key themes from the findings have emerged in relation to children's participation in care, including their felt and perceived autonomy, responsibility, and competence. Children's involvement in care is reported as being valuable to children, parents', and healthcare professionals; though some variability has been reported in determining children's competency and autonomy in regard to self-care. Such findings will be explored in terms of child agency and its implications for informal and formal care practices associated with epilepsy care. Connected to this, attention will also be paid to the ethic of care and wider care literature, to further explore how parents and children negotiate the changing care roles and responsibilities.

### **Family Member Uncertainty Throughout the Transplant Process: Sources, Implications and Management Strategies**

*Patterson, R., Exley, C., Fisher, A., Stobart, L.*  
(*Institute of Health and Society*)

Organ transplantation is a well-established treatment for numerous long-term conditions. However, the experiences of waiting for and undergoing transplantation can have significant psychosocial and physical implications for the patient. Acknowledging this, good social support is considered an essential requirement for admission to the waiting list. Consequently, family members are often heavily involved in the transplantation process, from initial assessment and throughout recovery. Despite the importance of their involvement, little is known about the impact of the transplantation process on families. Few sociological studies exist exploring the broader psychosocial impact of the transplantation process on the families of those waiting for, or who have received, a solid organ transplant. This study aims to address this gap. Qualitative methods were used to critically examine the views and experiences of 24 family members of heart, lung and/or liver transplant patients. Participants were recruited through UK based transplant charities. Family members recruited before transplantation were interviewed longitudinally about their experience, while those recruited after transplant were interviewed retrospectively. A narrative interview approach was employed to facilitate open discussion. Interviews were conducted face to face or by telephone, audio recorded and transcribed verbatim. Thematic analysis identified a number of emergent themes, of which uncertainty was considered to be key. This paper will summarise the sources and implications of this uncertainty. In addition, effort will be made to examine strategies family members used to manage such uncertainty. Where appropriate, relevant theoretical perspectives of uncertainty will be referred to and their applicability explored.

## **Gender**

**BYNG KENDRICK - G11, MAIN BUILDING**

**Thursday 08 September 2016 at 10:45 - 12:25**

### **Toxic Money or Paid Altruism: How Sperm and Egg Donors Negotiate Payment**

*Gilman, L.*  
(*University of Edinburgh*)

This paper examines the social significance of money in the context of gamete donation. Drawing on 24 in-depth interviews with UK identity-release gamete donors, I analyse the ways in which donors negotiate the issue of payment. Whilst my participants were unanimous that donation should be undertaken as a gift and that nobody should be 'doing it for the money', they were split as to whether the acceptance of payment could be accommodated within this gift narrative. There was a strong gender dimension to this division. Male donors frequently asserted that to accept any payment would taint their gift. In contrast, many female donors took a more nuanced approach and suggested that acceptance of some payment could be compatible with a spirit of altruism. I argue that in order to explain these findings, we must first understand the discursive means by which the donors presented their actions as gifts: Sperm donors tended to present donation as a 'pure' gift, presented in opposition to financially motivated exchange – it was a gift precisely because they gained nothing from it. Egg donors were more likely to portray donation as a 'relational' gift – it was a gift because they felt a personal connection with the recipient. I suggest that cultural barriers particularly constrain male donors from adopting the latter gift discourse and encourage the former; Specifically, I discuss how the stereotype of a sperm donor, donating for 'beer money,' and the continued stigma of male infertility create such barriers.

### **Health Help Seeking Behaviour and Health Services Utilization of Bruneian Men: A Grounded Theory Study**

*Idris, D.*  
(Durham University)

Despite the growth in research on masculinities and health seeking behaviour we have little idea of how gender and ethnicity intersect to inform health seeking behaviour in multi-ethnic cultures. This paper presents findings from a PhD research project investigating how being a man in Brunei Darussalam, a country with a strong religious and diverse cultural society, influenced men's perceptions of and attitudes towards their health and health help seeking behavior. Using Grounded theory, this study utilized semi structured interviews and focus groups with a total of 44 men and women from diverse ethnic backgrounds in Brunei Darussalam.

Three key themes emerged from the analysis of interviews with men: (1) The physicality of health and its importance to men; (2) The concept of "Ikhtiar" in looking after oneself; (3) Men as legitimate users of healthcare services.

Themes emerging from interviews with women focused on the relationship between wives and husbands, and daughters and fathers, and the way caring responsibilities reinforced bonds within the family. Women saw men's reluctance to use healthcare as 'normal for men', while men acknowledged that pressure from wives was a factor in their decision to seek help.

This paper contributes to the development of knowledge about masculinities and health in a region where to date there has been little research, despite the existence of epidemiological evidence indicating that men's health needs are often unmet.

### **Biopedagogy and the Metabolic Syndrome (Metabo) in the Japanese Media**

*Castro-Vazquez, G.*  
(Nanyang Technological University)

Most recent official reports emphasise an increase tendency to masculinised obesity and overweightness ('fat-men' aged 40-60), and feminised underweightness ('skinny-women' aged 20-30; MHLW 2013). In this light, this paper analyses 805 reports from 2009 to 2016 in three major Japanese newspapers (Asahi, Yomiuri, Mainichi) to unveil an aspect of the cultural dimension underpinning bodyweight related matters in Japan. Metabo (metabolic syndrome)—popular term to refer to obesity and overweight—was the keyword in the search and 'biopedagogy' (Wright 2009) appeared one of the main constructs to understanding the sociality of obesity and overweight. Biopedagogy helps reproduce the individualisation of bodyweight-control, and the understanding that metabo chiefly stems from illiteracy and weak-willed. 'Affirmatory metaphors' presented in 'anecdotes of biographical success' (Iphofen 2001) are key to proving that controlling bodyweight is effectively a matter of 'trying hard' (ganbaru). Illiteracy is expressed in terms of poor-knowledge concerning food intake and physical activity and both constructs tend to imply that a 'traditional lifestyle' could be a 'solution' because 'western food' and the 'sedentariness of modernity' largely represent bodyweight issues in Japan. The tendency to masculinised-metabo is confirmed, as the main character in the narratives tends to be either a middle-aged man (ojisan) or a father (otosan), this last in particular, however, seems to contradict individualisation as a 'metabo-father' appears to be the concern of the entire family especially the mother in the household, who is expected to enforce biopedagogy by monitoring her husband's physical activity and encouraging the consumption of traditional Japanese food.

## **Health Care Organisations**

**STAFFORD 2, CAMS**

**Thursday 08 September 2016 at 09:00 - 10:40**

### **Medication Safety in Action: Transcending Facts and Figures Through Health Professionals' Everyday Working Practices**

*Farre, A., Cummin, C.*  
(University of Birmingham)

Medication safety is often understood, studied and discussed in terms of medication errors (ME) and adverse drug events (ADE). However, we argue, a more comprehensive look at the processes and practices involved in the medication process might not only shed light on why and how ME and ADE happen, but also enable new pathways to address and manage medication safety in health care organisations. This is particularly important given the rapid growth of technologies that are expected to improve medication safety, such as ePrescribing, the implementation and impact of which could be better understood in the context of a greater understanding of previously existing practices.

We draw on two closely related qualitative datasets, both from a paediatric secondary and tertiary hospital in England: (i) a qualitative case study in a surgical ward, exploring the role of nurses in the medication process (prior to the

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implementation of ePrescribing), using focus groups and interviews; and (ii) the 'before' stage of a longitudinal ethnographic study, exploring the effects of implementing ePrescribing on in-patient care provision.

Across these two datasets we explore what practices are involved in the medication process from health professionals' perspectives, and how these are enacted in the context of their everyday working practices to ensure safety. Our findings suggest that medication safety is a collective practice accomplished through a dynamic set of interactions, practices and situations through which medication risks are managed – often beyond the boundaries of key organisational elements such as roles, formal knowledge or reporting systems.

### **What Counts as Evidence in the Public Health Commissioning Context of Local Authorities: 'Mindlines' and Knowledge Use in Context**

*Sanders, T., Grove, A., Hampshaw, S., Salway, S., Goyder, E.*  
(University of Sheffield)

#### Background

What counts as evidence in the new local authority context of public health commissioning may stand at odds with scientific notions of valid knowledge. The aim of the paper is to establish how these two approaches intersect. The integration of public health in local authorities has led to growing interest in the impact on commissioning practices, professional identities and the conceptualisation of evidence by different professional groups, potentially leading to a 'clash of cultures'. Gabbay and Le May's concept of 'mindlines' will be used to illustrate knowledge use in the commissioning context.

#### Methods

Observations of commissioning meetings, 15 interviews and 2 focus groups with stakeholders at a local authority were conducted to explore acceptability of a health economic modelling tool to inform commissioning for type 2 diabetes services. The data were analysed thematically.

#### Results

A number of influences affected the acceptability of the model, including 'whole systems' thinking: the need for the model to consider the interdependency of different services and commissioning approaches rather than viewing services in isolation, and 'evidence culture': the broad definition of evidence used in the local authority meant that the model was viewed as one resource among many.

#### Conclusion

Commissioning decisions are informed by different types of evidence, and the tool could be a valuable resource for evidence based commissioning. Its acceptability, however, will be influenced by the extent to which it can respond to the 'whole systems thinking' that is so integral to the routine work of commissioners.

### **All Aboard! Value-Based Healthcare and Patient Values – Adding a Strategic Edge to Measuring Health Impact?**

*Nordin, P., Koskela, I., Kork, A.*  
(University of Tampere)

Recently, there have been calls for value-based healthcare model (Porter & Teisberg 2006) to enact a paradigmatic change in how health impact is assessed. Traditionally, cost-effectiveness and quality of care have been assessed from healthcare providers' perspective, while patient surveys have measured mainly satisfaction with care. To assign an observed health impact of the Evidence-Based Medicine (EBM) to particular interventions, value-based healthcare measurement recognizes patient values alongside cost and quality of care as a driver for increasing health impact at societal, organizational and individual levels.

Relying on case study design, this paper assesses both the implementation process and the impact of value-based measurement in healthcare delivery in Finland in a strategic management context. By looking at two healthcare organizations we illustrate the implementation process of value-based measures. Particularly, we will analyze case organizations' attempts to create a strategic edge to measuring health impact by adding patient values to the planning of care processes.

First case investigates implementation of a specific EBM-intervention - Patient-Reported Outcome Measures (PROMs) – in a public hospital to measure health impact and improve organizational care processes. The second case focuses on a private primary healthcare provider's strategic use of Big Data screening tools that offer a novel perspective for assessing risk groups and their good care balance. Both cases are concerned with optimization of organization's knowledge management processes that allow for new ways of measuring health-related quality of life (HRQoL) and re-structuring the care processes, while creating value for all stakeholders.

# Health Policy

## STAFFORD 2, CAMS

Thursday 08 September 2016 at 10:45 - 12:25

### **Being Autonomous and Having Space in Which to Act: The Role of Commissioners in the 'New NHS'**

*Checkland, K., Hammond, J., Dam, R., Segar, J., Coleman, A.*  
(University of Manchester)

The English Health and Social care Act 2012 (HSCA12) created Clinical Commissioning Groups (CCGs), which were claimed to be both more autonomous and more accountable than their predecessors. Autonomy refers to the extent to which organisations may act without constraint. Bossert (1998) explores 'decision space', arguing that local space to act arises from the interaction between choices permitted and rules governing those choices. However, formal rule-based autonomy is only part of the story, as local organisations must also feel themselves to be able to act (Exworthy et al 2011). Perceptions of autonomy will be influenced by local organisational interactions and by interpretations of the regulatory environment.

Using qualitative case study methods, we explored commissioning in two 'local health economies' in England. CCG leaders suggested that CCG establishment as statutory bodies gave them legitimacy within the local health economy, providing a sense of autonomy and 'space' in which to act. However, they also described progressive development of constraints, including: increasing focus upon financial balance with limitations for underachievers; increasing pressure to meet national targets; an increasingly strict assurance regime; the imposition of new organisational tiers, imposing additional targets and requiring regular reports; and constraints arising out of the development of multiple local partnerships. We investigate the role of CCGs in a complicated landscape, exploring not only their autonomy to act but also how far they feel able to use this autonomy. We will examine the constraining factors identified and seek to define the limits of the 'decision space' inhabited by CCGs.

### **Articulating Cancer Care Through Standardized Patient Pathways**

*Håland, E., Melby, L.*  
(Norwegian University of Science and Technology)

The introduction of standardized cancer patient pathways (CPPs) in Norway is an attempt to make diagnosis, treatment and follow up of cancer predictable, high quality and timely processes. 28 CPPs were introduced during 2015, covering the most common cancer types. CPPs are examples of standardization of processes, a prominent feature of today's healthcare, introduced to secure that patients receive the same treatment across settings. At the same time current healthcare policies, including cancer care, highlight individualization/personalization of medicine, where individual follow up, the patients' personal preferences and health personnel's medical discretion are highly valued. Thus, CPPs are introduced in a context where two parallel, and possibly contradictory, discourses in Norwegian healthcare are present.

The aim of this paper is to discuss how the discourses of standardization and individualization of care are drawn upon to articulate what counts as 'high quality cancer care' in texts following the introduction of CPPs. The analysis is based on text analysis of policy documents, the official descriptions of the specific CPPs and selected texts from the media. We find that standardization and individualization are articulated as negative or positive to the individual patient in different ways throughout the texts, dependent on which type of argument the producers of the texts are trying to make, in order to make the introduction of CPPs appear as a good solution for high quality cancer care. Standardization and individualization can thus be seen as complex phenomena, implying continuous negotiations of meaning of, and dominance between, the two discourses.

### **A Case Study of Physiotherapist Non-Medical Prescribing: Service Re-Organisation, a Primacy of Orthopaedic Surgery and the Marginalization of Prescribing Medicines**

*Wilson, N., Pope, C., Roberts, L., Crouch, R.*  
(University of Southampton)

Rights to prescribe medicines now extend to a range of healthcare professionals including some physiotherapists, who can act as supplementary and independent prescribers. Non-medical prescribing is a key pillar of NHS modernisation policy, designed to deliver quicker access to treatment and result in improved health outcomes for patients.

In this paper we investigate the non-medical prescribing practices of physiotherapists working in an outpatient service in England. The enactment of non-medical prescribing in this context occurred against a backdrop of significant national and local service re-organisation (including shifts between primary and secondary care provision associated with wider NHS reforms) and financial austerity.

Our analysis is framed by an interest in professions as social bodies that engage in jurisdictional boundary-work and is informed by Foucault's conceptualisation of governmentality. The data presented is drawn from non-participant

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observation of physiotherapist working practices during eleven half-day outpatient clinics, informal conversations before, during and after clinics, analysis of documents associated with the case study and twelve semi-structured interviews with participating physiotherapists and other healthcare professionals involved in the policy and practice of non-medical prescribing.

Using Yanow's (2000) steps for interpretive policy analysis, we explore the microphysics of power shaping and constituting these physiotherapists and their non-medical prescribing practices. We identify a dominant discursive framework within which elective orthopaedic surgery is given primacy over non-surgical management of people with musculoskeletal conditions and the prescribing of medicines by physiotherapists is marginalized, despite the national policy rhetoric.

## Methods

### WHITEHALL 1, CAMS

**Thursday 08 September 2016 at 09:00 - 12:25**

#### **Needle in a Haystack? Using Positive Deviance Methodology to Uncover Differences Between Healthcare Organisations**

*Sheard, L., Dewhurst, L., Lawton, R.*  
(Bradford Teaching Hospitals)

Positive deviance (PD) is a way of examining variation across healthcare settings by understanding how and why highly performing clinical teams achieve their results. Despite having similar challenges and resources, some healthcare teams are performing better than others in achieving high quality clinical outcomes. They are deviating from the norm but in a positive manner. PD as a methodology has captured the attention of health researchers and latterly medical sociologists as it is inherently socially situated.

I provide a critique of PD methodology by exploring the findings of a PD study which sought to assess the differences between two orthopaedic services in Yorkshire & Humber – one being the top performing service (in relation to low readmissions and high patient reported outcomes) and the other performing averagely. Intense ethnographic fieldwork took place over an 8 month period.

Although many differences can be observed, initial findings demonstrate that overall the two services have more similarities than differences – positive practices can be identified at both sites. Our use of the ethnographic method may have made it difficult to point to identifiable mechanisms or concrete items which make for a difference in performance between the two sites because how services achieve their results is inherently complex, relational and multi-factorial. This is further compounded by the meso level cultural interplay between the orthopaedic service and the wider hospital organisation. This presentation will discuss the difficulty in searching for 'difference' at the level of a whole healthcare service using social science techniques.

#### **'Black Box Thinking': Do Significant Event Audits Provide a Blame-Free Environment in Which GPs Can Talk About Cancer Diagnoses?**

*Yiallourous, J., Arnold, A., Forster, L.*  
(Cancer Research UK)

Since it was first reported that around one quarter of cancers are diagnosed after an emergency presentation, GPs have received much negative press about their role in cancer diagnosis. Thames Valley Strategic Clinical Network commissioned Cancer Research UK to undertake a study of people who had been diagnosed with cancer through an emergency GP presentation route in the Thames Valley area.

Significant Event Audits (SEA) were used to collect the data. SEA is a tool used routinely within primary care to reflect on an event, learn from the experience and undertake changes within the practice to improve patient care; more recently SEAs have been used for research purposes. The 172 completed SEAs provided nearly 100,000 words of free text comments and were analysed using thematic analysis for the study presented here.

By examining both the documented events and the reflections of GPs and other staff within the practice setting our study highlights how the pre-diagnostic part of the cancer journey was experienced by primary care professionals. It appears that the SEA was felt to be effective because they were 'able to explore issues openly and without blame' contrasting with other GPs reporting 'Reassurance that primary care team were not negligent in coming to the diagnosis'.

The study concludes that SEAs provide a rich source of data for qualitative analysis and that within the constraints of the 'blame culture' a non-judgemental environment for reflexive responses could be used more widely for GP research.

### **Secret Subject and Invisible Participants: Reflections on Doing Research in Corporate Medical Organizational Settings**

*Mwale, S.*  
(University of Brighton)

This paper examines the challenges of conducting social research involving pharmaceutical research organisations in the UK. It draws on experiences of from a research on human involvement in clinical trials focused on regulatory, economic and ethical issues of first-in-human clinical trials. While within social research transparency and sharing of information is considered central to resolving social problems, the explicit ways in which secrecy surrounds the practice of clinical trials as themselves a form of research, relates to a theory of knowledge and ways of experiencing knowing that directly oppose these principles. This is because the organisation and practice of clinical trials, from a public perspective, is shrouded in secrets some of which may be justifiable some not. Specifically, this paper examines the ways in which trust, concealment and the gate keeping in 'contract research organisations' (undertaking trials on behalf of drug companies) shape knowledge production. The paper will examine the characteristics of key players in the early clinical trial process, and how this makes them hard to access. The paper asks: what is the value of social research if the research informants do not see value in it? Using data from interviews with both professionals and 'lay' healthy volunteer participants in clinical trials, email exchanges and documentary analysis the paper discusses the implications of secrecy on knowledge production and explores the relationship between secrecy and trust and ways in which trust is both built and tested in pharmaceutical research.

### **Access Relations in Ethnographic Research in Paediatric Hospitals: Reflections on Constraints, Ethical Issues and Identity Work**

*Grant, A., Jacob, N., Moriarty, Y., Lloyd, A., Allen, D., & the PUMA study group*  
(Cardiff University)

In recent years, the complexity of gaining, securing and maintaining (Blix and Wettergren, 2015) access in field sites has been increasingly reported in the methodological literature. It is particularly challenging to maintain access in public organisations (Bondy, 2012), and when working with vulnerable groups (Wagle and Cantaffa, 2008). To date, however, little has been written in terms of access in medical settings. This paper draws on ethnographic observations on paediatric wards of four UK based hospitals as part of the PUMA (Paediatric Early Warning Systems: Utilisation and Mortality Avoidance) study.

In our analysis of access arrangements, we draw on Blix and Wettergren's categorisation of access as three part, but also suggest that maintaining access can be further divided into gaining superficial or deep accounts of routine behaviour (Molloy, 2015). In our research sites, access was gained at senior levels with relative ease. However, in maintaining relationships with a range of staff (health care assistants, nurses, doctors), patients and parents, considerable identity work was undertaken. On occasions, access to observe particular interactions of interest was revoked, highlighting the precarious nature of access agreements with multiple gatekeepers. Furthermore, whilst embedded in the field, the researchers had to ask ethical questions, around when it was not appropriate for them to observe particular interactions. We conclude that issues of access, ethics and appropriate conduct are challenging when conducting ethnographic research in medical settings where the pace of movement is often fast, and that researcher should reflect on their position before and during fieldwork.

### **Participants' Use of Enacted Scenes in Research Interviews: A Method for Reflexive Analysis in Health and Social Care**

*Pilnick, A., James, D., Hall, A., Collins, L.*  
(University of Nottingham)

In our study of a workforce intervention within a health and social care context we found that participants who took part in longitudinal research interviews were commonly enacting scenes from their work during one-to-one interviews. Scenes were defined as portions of the interviews in which participants directly quoted the speech of at least two actors. Our analysis in this paper focuses on these enacted scenes, and compares the content of them before and after the intervention. We found that, whilst change, and change management, were common topics for scene enactment in both pre and post-intervention data, following the intervention participants were much more likely to present themselves as active agents in that change. Post-intervention enacted scenes also showed participants' reports of taking a service user perspective, and a focus on their interactions with service users that had been absent from pre-intervention data. We suggest that this analysis confirms the importance of enacted scenes as an analytic resource, and that their importance goes beyond their utility in identifying the impact of this specific intervention. Given the congruence between the themes prominent in enacted scenes, and those which emerged from a more extensive qualitative analysis of these data, we argue that enacted scenes may also be of wider methodological importance. Sociologists of language have a growing interest in the use of reported speech, and we suggest that the specific study of scene enactment could provide a useful methodological resource in settings where longitudinal ethnographic observation of frontline practitioners is impossible or impractical.

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### **Opening the 'Black Box' of Patient Safety in UK General Practice: The Application of Long-Term and Short-Term Multi-Sited Ethnography for Understanding Healthcare Organisational Complexity**

*Grant, S.*  
(University of Dundee)

Ethnography is a well-established approach to conducting research within healthcare organisations. While ethnography is usually associated with a long-term research process involving extended periods of fieldwork, more 'rapid' (Bentley et al. 1988) or 'focused' (Knoblauch 2005) approaches are increasingly being sought by researchers and policymakers that are responsive to the short-term cycles of healthcare policy implementation and change. Healthcare organisations are increasingly described as 'complex systems' (Rowley & Waring 2011). Within the field of patient safety, there is increased recognition of the need to understand the 'black box' (Swinglehurst et al. 2011) of organisational safety practices over time through long-term ethnographic engagement. It is also recognised that the tacit knowledge, innovation and flexibility used by local actors in the creation of safety varies across organisational settings, and that a wider range of methodological, practical, and analytical entry points are required to provide a fuller understanding of change across different organisational contexts.

The aim of this paper is to examine interprofessional safety practices across a range of high-volume organisational routines within UK general practice (e.g. repeat prescribing) through the application of both long-term and 'short-term' (Pink & Morgan 2013) multi-sited ethnographic methods. Drawing on findings from an ethnographic study conducted across 8 general practices (2010-14) and Pink's (2009) concept of 'ethnographic place', it explores how different 'types, qualities and temporalities of things and persons' come together through both long- and short-term methodological approaches, and how ethnographic findings can best contribute to a wider body of 'evidence' for healthcare policymakers and practitioners.

## **Open** **WHITEHALL 3, CAMS**

**Thursday 08 September 2016 at 11:55 - 12:25**

### **Participatory Health Research and Challenges to the Sociology of Health and Illness**

*Feiring, M., Heiaas, I., Koren Solvang, P.*  
(Oslo and Akershus University College of Applied Sciences)

Participatory health research is on the rise. Numerous funding institutions have made it obligatory for applicants to develop research outlines that include the involvement of persons whose life or work is part of the research process. These requests pose a challenge to the sociology of health and illness. First, the active voice of patient and public organizations may be a threat to the legitimacy of research results. Second, the attentive qualitative researcher may be better able to represent the voices of vulnerable group members, than semi-professionalized NGO representatives. Finally, giving participants a strong voice in all parts of the research process may violate important standards of analytic objectivation in sociological studies.

The purpose of this paper is to describe these challenges that are posed by 'user participation' in research, and discuss them through the lens of the differing forms of knowledge interests, as outlined by the German philosopher Jürgen Habermas and exemplified by three empirical cases. Our argument is that participatory research means quite different things within various research traditions. In the clinical biomedical sciences, collective user representation is the main mode of participation, and this may become a threat to the political legitimacy of research results. How to listen to the voices of the vulnerable is addressed both by the interpretative studies of the humanistic tradition and the emancipatory knowledge interests intrinsic to the social sciences. The claim of analytic objectivation relates to the importance of an epistemological break from primary experiences and everyday knowledge of research participants.

## **Patient - Professional Interaction** **WHITEHALL 3, CAMS**

**Thursday 08 September 2016 at 09:00 - 11:50**

### **What Can we Learn from the Introduction of Alternative Methods of Consulting in UK General Practice?**

*Ziebland, S., Atherton, H., Brant, H., Porqueddu Annemeike Bikker, T., McKinstry, B., Campbell, J.*  
(University of Oxford)

Alternatives (such as email and video conferencing) to face-to-face consultations have been enthusiastically promoted as a cost effective way to improve General Practice services to patients. We are conducting a focussed ethnography (observations, formal and informal interviews) in 8 practices in England and Scotland. We aim to understand how alternatives to face-to-face consultations are being used (and resisted) and what may be the gains and losses for patients and staff.

The case study practices were chosen to include practices offering various combinations of telephone consultations, e-consultations via software applications (e.g. WebGP), email consultations and video consultations. Interviews and observations suggest that staff are often unaware of whether and how frequently their colleagues may be using these methods. E-consultation software uptake by patients is low; email consultations are rarely used, other than by 'lone wolf' GPs who use it with selected patients (who sometimes have complex or terminal health conditions) but are also those deemed 'sensible' or trustworthy, raising questions of equity). Observations suggest that receptionists rarely offer the option of consulting online. Professional views differ about which 'types' of patients are suitable for an alternative consultation method. Neither the anticipated efficiency benefits, nor concerns about inundation, safety and inappropriate use have been realised in the practices. In this talk we will discuss the intended purpose of alternative methods of consultation and consider whether the face to face consultation should be an abiding gold standard.

### **The Elicitation and Management of Patients' Multiple Health Concerns in GP Consultations**

*Woods, C., Gennery, E., Stewart, B., Summers, R., Drew, P., Barnes, R., Stevenson, F., Chew-Graham, C., Leydon, G. (University of Southampton)*

Whilst patients often attend General Practice (GP) consultations in the UK with multiple concerns, they may not feel able to raise all of these during the consultation and, even when they do, some concerns may remain unaddressed. Unaddressed concerns can have deleterious consequences for patients and their GP. These include worsening symptoms, poor health outcomes (e.g. decreased satisfaction for patients, poor adherence with treatment) and can result in repeated consultations.

This presentation will report on a secondary analysis of an analytically driven sample of 186 GP-Patient video-recorded consultations with 186 patients and 15 GPs collected in 2013/4 across 11 practices in the South of England. All videos were initially coded quantitatively, verified by the team, to permit navigation of the data corpus for focused and fine-grained qualitative work using Conversation Analysis (CA). With its origins in Sociology, in particular Ethnomethodology, CA is an inductive, micro-analytic method for analysing real-time interactions across mundane and institutional settings.

The presentation will discuss the CA findings on how UK GPs and patients collaboratively manage the voicing and discussion of multiple concerns in these so-called 'complex consultations'. Analysis will focus on practices that may work to enhance or inhibit the full disclosure and discussion of patient concerns. By paying close attention to the interaction (including verbal and non-verbal aspects) during these medical visits we will begin to unpack the communicative patterns involved in GP-Patient interactions in which doctors clearly solicit multiple medical issues during medical visits and how patients can (and do) volunteer additional problems.

### **Epistemic Models in General Practice: Exploring Perspectives on Medically Unexplained Symptoms**

*Rasmussen, E., Isaksson Rø, K. (Oslo and Akershus University College of Applied Sciences)*

Medically unexplained symptoms (MUS) are known to be common yet exceptionally challenging to work with, and a source of great tension in general practice. This paper explores how general practitioners (GPs) conceive of MUS in the context of clinical work; what types of patients present with MUS, what should be done with them, and what clinical challenges must be overcome? By drawing on and analysing data from three focus group interviews with twenty-three Norwegian GPs, we find that the GPs adopt disparate epistemic models of MUS: The reductionistic and scientific biomedical model, and the holistic and pragmatic biopsychosocial model. These epistemic models affect the GPs' views of the typical patients and their conditions, of the available courses of action, and of themselves as physicians. Specifically, the models imply different diagnostic- and treatment strategies GPs employ when patients present with MUS. We argue that GPs who adopt the biopsychosocial model are more comfortable under conditions of medical uncertainty than those that do not, and discuss the intersections between knowledge, action and identity in general practice. The paper contributes to the expanding sociology of diagnosis, for which MUS has been a substantive interest, and the emerging sociology of medically unexplained symptoms.

### **Missed Opportunities – Perspectives of Facilitators and Participants about Social Support and Goal Setting in HCP-Led Chronic Condition Self-Management Group Programs**

*Hughes, S. (University of Sydney)*

The role of social support and setting goals in group settings is under-represented in the sociological analysis of long-term condition management. Gallant (2003) suggests that attention be paid to elucidating the implicit mechanisms and social environment through which support influences self-management. Group programs led by healthcare

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practitioners (HCPs) for people with long-term conditions promote self-management capacities and behaviour change through education, increasing self-efficacy and goal setting. We draw on theory, Thoits (2011) who identified two support types - emotional sustenance and active coping assistance, to examine the (in)visible and deliberate forms of support in group settings. In order to do this we conducted a qualitative study of participation in HCP-led groups for diabetes type 2, COPD, and obesity. Observations and in-depth semi-structured interviews were conducted with HCP facilitators and group participants. Findings revealed that facilitators created an environment providing instrumental aid and information, emphasising achievements through measurable outcomes. There was little evidence of encouraging emotionally sustaining experiences or pursuing non-biomedical goals. In contrast, the notion of 'being with people like me' was integral to the participants' experience. Participants spoke of less visible yet highly valued group experiences, including 'realising I am not alone', 'enabling us to be ourselves', and 'a place to not feel like a burden'. We argue that focusing on an instrumental change model means opportunities for the achievement of social benefits valued by participants are missed and that more of the external environment shaping behaviour needs to be forefronted in analysis of self-management support.

### **Using Cultural Health Capital to Understand how People with Chronic Conditions and their Healthcare Providers Negotiate Self-Management Goals**

*Franklin, M., Willis, K., Lewis, S., Smith, L., Hughes, S., Rogers, A., Wyke, S.*  
(Australian Catholic University)

Goal setting in organisations has long received sociological attention (e.g. Perrow 1961). In a contemporary context individual goal setting is seen as central to policy initiatives in many countries including Australia to promote self-management. Although collaborative goal setting is promoted as a key component supporting effective self-management, in practice there are often disparities in the goals valued by healthcare professionals (HCPs) and people living with chronic conditions. Addressing a key gap in the medical sociology literature this paper examines goal setting as an interactional process by applying the concept of cultural health capital (CHC) (Shim, 2010). We use data from observations of consultations and indepth interviews with both HCPs and people with chronic conditions (COPD, obesity and DMT2) to examine how the process of goal setting is shaped by patient – provider interactions. Initial findings suggest that the negotiation of goals depends on how individual attributes and resources of both people with chronic conditions and HCPs are valued and exchanged in a context that privileges biomedical goals and individual responsibility. Emerging themes include the 'giving of goals'; 'being held to account'; and 'directive advice', tempered by messages of morality (e.g. the 'right' choices). Despite the intent of collaborative goal setting HCPs appear to be directive in goal setting, negating the social context that people bring to the interaction. This is particularly so for interactions in which both the person with a chronic condition has low CHC.

## **Pharmaceuticals** **STEELHOUSE 3, CAMS**

**Thursday 08 September 2016 at 09:35 - 11:50**

### **Geneticisation of Pharmaceutical Testing: A Sociological Investigation of the Implications for Public Health**

*Abraham, J.*  
(King's College London)

During the 21st century, the development of pharmaceuticals has increasingly paid attention to growing knowledge about genetics, disease and bodily response. Most commonly this has been discussed in terms of pharmacogenomic/genetic profiles and the implications for clinical personalised medicine. A neglected field, however, is the implications of geneticisation for non-clinical pharmaceutical development, testing and evaluation. The purpose of this paper is to address that neglect and to demonstrate why the reshaping of carcinogenic risk assessment is simultaneously an important concern for sociology and public health. Drawing on years of documentary and interview-based fieldwork in Europe and the US with industry, regulators, and other scientists and experts (funded by the Wellcome Trust), this paper will examine how geneticisation has been integrated into new regulatory standards for the toxicological testing of pharmaceuticals in carcinogenic risk assessment in the 21st century. Utilising realist sociological theories of science, it will explain how various cognitive, institutional, economic and political commitments have shaped the way in which toxico-genomics has been marshalled to reconstruct what counts as knowledge about pharmaceutical carcinogenicity. In particular, it will be argued that these new standards have been made possible by the intersections of scientist activism with the economic power and interests of the transnational R&D-based pharmaceutical industry in the context of a neo-liberal regulatory state. Finally, the paper will investigate some of the experience of using these new standards and consider whether they represent an advance or regression on previous standards in terms of protecting public health from pharmaceutical carcinogens.

### **Antiretroviral Baggage and Imagined Futures: Situating Antiretrovirals within the Discourses of HIV Treatment as Prevention**

Lloyd, K.

(University of California, San Francisco)

HIV treatment as prevention is an emerging biomedical prevention approach advocating routine HIV testing, linkage to medical care, and consumption of antiretrovirals to suppress individuals' viral loads, the number of HIV viruses circulating in the blood, to such a low level that they cannot be detected by viral assays, to a point of being 'undetectable'. Being undetectable greatly reduces or eliminates the risk of onward transmission of HIV. HIV treatment as prevention thus advocates the use of antiretroviral therapy for the protection of a broader public – a radical departure, historically, from the use of antiretrovirals as clinical tools. This paper explores how antiretrovirals themselves, as pharmaceutical technologies of discursive significance, can be methodologically foregrounded as material things in which numerous individual and collective actors have a stake. Adele Clarke (2005:153) stresses the importance of studying 'the social life of things' and within the discourses of HIV treatment as prevention, antiretrovirals are being made up as things which both potentiate and disrupt the possibilities for their use as prevention technologies. Drawing on interviews with HIV scientists, policymakers, clinicians, and advocates as well as narrative and visual discourse materials, this paper seeks to situate antiretrovirals themselves as they are constituting and being constituted within the broader discourses of HIV treatment as prevention. Utilising situational analysis, and situational and positional mapping, specifically, this paper will topographically explore the construction of antiretrovirals as evolving and potentiating their use as prevention technologies as well as carrying with them historical 'baggage' which disrupts this potentiation.

### **From Standardization to Adaptation: Clinical Trials and the Moral Economy of Anticipation**

Montgomery, C.

(University of Oxford)

The Randomized Controlled Trial (RCT) occupies a hegemonic position at the top of Evidence Based Medicine's hierarchy of knowledge. Within sociology, however, clinical trials have been seen as a highly contested form of knowledge-making, with critiques focusing on structures of epistemological dominance; the rise of evidence-based medicine and audit culture; the neoliberalisation of healthcare; and the exploitation of patients. The methodological rigidity and immutability of the RCT is underscored as a means of doing violence to the social world and our understanding of it. This paper asks about the conditions under which it is possible to speak about change in the 'gold standard'. To do so, it presents a genealogy of adaptive design in clinical experimentation through an analysis of medical, statistical and other scientific journals, supplemented with key informant interviews.

Changing discourses of time and patienthood have facilitated a move away from standardization as the singular logic of trials towards an appreciation of flexibility, undergirded by probabilistic methodologies. A genealogical analysis exposes the discursive moves used to justify and popularize adaptation, from an initial focus on patient wellbeing and the greater good to efficiency and virtualism. Adams et al's (2009) conceptual framework of anticipation illuminates this evolving moral economy of medical research, in which modes of knowledge production which claim to know the future are supplanting the traditional certainties of fixed and standardized experimental designs. Predictable uncertainty is the currency of this emerging economy, which capitalizes on computer simulation and ever more sophisticated tools of prediction to leverage credibility.

### **Prescribing Pleasure - Issues in the Medical Supply of Heroin to Addicts**

Cooper, R.

(University of Sheffield)

Historically, there have been examples of heroin prescribing to treat addiction although changing patterns of heroin have seen such practices diminish. Frustration with existing illicit heroin policies and promising clinical trials using have renewed interest in prescription heroin in the management of addiction. It is argued that a more nuanced account of heroin prescribing is required, drawing upon philosophical and sociological perspectives to offer a comprehensive balanced understanding and to counter dominant legal and moral accounts. In doing so, opposing views as to the merits of prescribing heroin for addiction arise but will ultimately better inform policy decisions in this area. Foddy and Savulescu's controversial claim of addiction as an appetite to satisfy desire support initiation and maintenance heroin prescribing. Although this is challenged by Kennett et al, it is argued that their empirical study suggesting diminished pleasure seeking and changes over time is not incompatible with heroin prescribing. Wakeman's ethnographic evidence tempers recent heroin prescribing trial positivity by highlighting important moral economy and identity issues associated with addiction, drawing on similar ontological concerns to Foddy and Savulescu. Considering the historical shifts and medical sociological dimension, policy change over time suggests a willingness to embrace such developments despite a dominant lay moral view of addiction. However, influential themes such as medicalization, medical control and surveillance are argued to be potentially detrimental to heroin prescribing overall. Finally, emerges a lack of empirical qualitative insights into individual experiences of heroin prescribing for addiction is needed to inform this re-emerging policy debate.

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# Screening and Diagnosis

WHITEHALL 2, CAMS

Thursday 08 September 2016 at 09:00 - 11:15

### **Diagnosis Lack of an Outside. The Social Context of the Emotion of Shame in Eating Disorders**

*Moen, H. B.*  
(Nord University)

This article portrays how the medical perspective on eating disorders (ED), and the clinical ED diagnosis based on individual signs, symptoms and behavior, are founded on a gathering of individual characteristics put into isolated individuals. Individual behavior, thoughts and feelings are thus identified as the problem. Hence, in therapy, the individual is seen as the objective of alternation or modification, expected to learn to think and feel differently. This represents an 'inside/outside problem'; due to the concern of emotions in isolated individuals (inside), the context in which emotions arise is ignored (outside). By the use of empirical examples from qualitative interviews highlighting episodes characterized by overwhelming emotions in ED, I argue that emotions do not only reside within individuals, but also emerge through social interaction. As an illustration of the inside/outside problem, this article explore the social context for the emotion of shame in particular. Conclusively, it is argued that only by interpretation of emotions in their social context is it possible to understand specific emotions origins, and correspondingly understand emotions and aid recovery in eating disorders.

### **A Comparative Analysis of Entanglements of Choice and Care in Patient's Experiences of Being Diagnosed with Cancer in Denmark, England And Sweden**

*MacArtney, J., Andersen, R. S., Rasmussen, B., Malmstrom, M., Tishelman, C., Eriksson, L. E., Ziebland, S*  
(University of Oxford)

Being diagnosed with a later stage of cancer is related to a poorer survival rate overall. Unfortunately, England has poorer rates of lung and colorectal cancer survival in comparison to Denmark and Sweden. Entangled within efforts and initiatives to improve early diagnosis are two discourses that are shaping healthcare more broadly in all three countries: choice and care.

Experiences of 'choice' in healthcare – along with the complementary discourses of autonomy and individual freedoms – have been understood, in part, as empowering strategies allowing resistance to medical paternalism and colonisation of the body. However, understandings of choice have been critiqued for being a key mechanism through which a neoliberal agenda can be implemented, transforming the moral economy of healthcare away from the patient and towards a financial bottom line. Similarly, experiences of 'care' have been contested. For some care provides an important bulwark against the more objectifying and dehumanising modes of medicine. Yet care is itself increasingly the object of professional, organisational and technological interests.

This presentation will draw on semi-structured qualitative interviews with people recently diagnosed (less than six months) with lung or colorectal cancer in Denmark (n=50), England (n=46) and Sweden (n=60). We will explore how participants understood their choices and care, what else was important to them when being diagnosed, and reflect on what these findings might mean for how we understand 'diagnostic pathways' and being diagnosed with cancer in the three countries.

### **Breast Cancer Screening in the Welfare State**

*Solbjør, M.*  
(Norwegian University of Science and Technology)

According to Klawiter (2008) breast cancer (in the US) has been part of a historical shift. The first period was medicalization of breast cancer, while from the 1980s, breast cancer has become part of the biomedicalization era. The theory of biomedicalization (Clarke et al, 2003) centres on five central processes: political economic shifts; the focus on health, risk and surveillance; the technoscience of biomedicine; production, distribution and consumption of information and knowledge; and transformations of bodies and identities. While the history of breast cancer and breast cancer screening has been thoroughly studied in the US, few studies have focused on screening within the welfare state context. This paper will explore whether and how the biomedicalization hypothesis is relevant for breast cancer screening in a welfare state context, exemplified through the case of Norway. In European welfare states, health insurance provides full coverage. The complex mix-up of biomedical, technical, professional, and economical interests is not necessary clear for screening consumers in the welfare state. Women within certain age-groups are invited regularly to breast cancer screening, at intervals defined by the public health services which are in charge of cancer screening programme. Thus, trust in authorities could be part of decision making about participation. In this paper, I will conduct an analysis with situational maps of actors, discursive constructions, politics and debates,

and cultural, historical and special elements, from breast cancer screening in Norway, and interpret them within a framework of biomedicalization.

### **Exploring HIV Testing Through Multiple Lenses**

*Mutch, A., Fitzgerald, L., Lui, C. W., Dean, J.*  
(University of Queensland)

Since 2010, HIV testing has been situated within a 'test and treat' agenda based on the premise that the rate of new HIV infections will be dramatically reduced by using aggressive methods to test and diagnose all people living with

HIV (PLHIV), treat them with anti-retroviral therapy (ART), and link them to care. The strategy is embedded within a biomedical framework which seeks to facilitate better clinical outcomes for the individual and reduce secondary transmission. The success of the strategy depends on participation by target population subgroups in testing and subsequent treatment, but contention surrounds notions of personal benefit versus public health benefit.

This paper draws on findings from the second qualitative phase of a larger study in Queensland, Australia which examines HIV testing practices and perspectives of new testing technologies in men who have sex with men. Seven focus groups with diverse population subgroups (young educated men, Indigenous peoples, people in rural and regional areas, and people engaged in sexually adventurous practices) were undertaken. The paper explores notions of personal versus public benefit and considers the way understandings of testing are filtered through a number of lenses based on the participants' multiple identities. The paper provides insight into the diversity of perceptions of risk and explores the way testing is negotiated through participants' complex and intersecting identities. The findings challenge test and treat policy which has become immersed within biomedical discourse and unable to acknowledge the diversity of needs and preferences of men who have sex with men.

## **STS and Medicine**

### **BYNG KENDRICK - G11, MAIN BUILDING**

**Thursday 08 September 2016 at 09:00 - 09:30**

### **Making up Families Through Expert Knowledge: The (Re)Configuration of Pasts and Futures Through Neuroscientific Advice**

*Broer, T., Pickersgill, M., Cunningham-Burley, S.*  
(University of Edinburgh)

Parenting is seen, on the one hand, as one of the most private spheres and, on the other hand, as the ideal site/time for state involvement to take place. Expert knowledge drawing on neuroscience has been increasingly employed as one way of advising (and governing) parents, in order for them to optimise children's brains and future lives. Based on 22 semi-structured interviews with parents who voluntarily participated in a parenting programme addressing issues such as attachment and child brain development, we present an analysis of the ways in which the future and the past figure in and are reconfigured through parents' negotiations with expert knowledge. Conceptualising this expert knowledge as technoscientific scripts, we show how parents draw on these scripts selectively and critically. Parents find the (neuroscientific) advice they received helpful in patiently dealing with getting children ready for school and with conceptualising the physical impact love and interaction have for example. Simultaneously, they critically question some of the temporal imaginaries inscribed in the advice, for example about the negative future consequences of putting children's needs central now and shielding them from realities of life and about how the advice relates to their own upbringing as well as the past of the human species more widely. Focusing on these ontological negotiations democratises the concept of expert knowledge (everyone can be an expert here, including the children themselves) and provides an exploration of how the notion of expertise itself is constructed in the context of parenting and parenting advice.

### **Shaping Science with Metaphors: Foetal Programming in the English News**

*Stelmach, A., Nerlich, B.*  
(University of Nottingham)

Metaphors such as 'code', 'blueprint' or 'book' have been essential for shaping research in genetic and genomic sciences, but also for shaping public understanding of what genes are and do, and how we become the way we are. In the context of recent advances in postgenomic sciences new metaphors have started to appear, especially in relation with the emerging field of epigenetics. The thriving field of foetal programming, related to both epigenetics and epidemiology, has provided new metaphors such as 'programming' and 'critical windows' which seem to turn attention away from genes and focus on the importance of development, especially the importance of early life, for determining

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health and disease in adulthood. This paper traces the emergence of such scientific metaphors and examines how they are deployed in the coverage of research into foetal programming in the English news. It asks: how are these metaphors used and interpreted in the press, and how do they contribute to framing public understanding of early life? By analysing which metaphors are used most frequently in the press and what paraphrases are used to explain them to the public this paper highlights the processes during which meanings of scientific metaphors are negotiated, resisted to and/or established in the media coverage. It explores the implications this might have for the metaphorical landscape of postgenomic science and for public understanding, as well as the significance of these findings for STS analyses of the life sciences.

### **Cardiff Sciscreen: A Model for Using Film to Engage Publics in Psychiatric Genetics**

*Lewis, J., Bisson, S., Swaden Lewis, K., Reyes-Galindo, L., Baldwin, A.*  
(Cardiff University)

Cardiff sciSCREEN is a public engagement programme that brings together local experts and publics to discuss issues raised by contemporary cinema. Since 2010, Cardiff sciSCREEN – short for science on screen – has exhibited 48 films alongside short talks and discussions that draw on a range of disciplinary perspectives to explore the broad repertoire of themes found within different film genres. The aim of the initiative is to increase the local community's access to university research - in particular, work centred on mental health - whilst enabling university staff and students to engage a variety of publics with their work. In this paper, we first describe our method of public engagement, then draw on data from a research survey we conducted to discuss the relationship between the theory and practice of public engagement. Using research from public understanding of science, science and technology studies, and film literacy, we discuss the ways in which our flexible characterisation of science has made the programme inclusive, attracting a wide and varied audience. We consider the benefits of cross-disciplinary perspectives when communicating and engaging contemporary developments in mental health and psychiatric genetics, where the term science is taken to stand for the breadth of academic research and not merely the natural sciences, and discuss the importance of space in public engagement events.

## Citizenship and Health STAFFORD 1, CAMS

**Thursday 08 September 2016 at 15:10 - 16:15**

### **Patient and Citizen Engagement in England, Finland and Sweden**

*Tritter, J., Fredriksson, M., Koivusalo, M.*  
(Aston University)

Patient and public involvement (PPI) has become an integral part of many developed health systems and is together with patient-centered care and self-management an essential driver for reform. PPI is framed as positive for individuals, the health system, public health, as well as for communities and society as a whole. The benefits associated with PPI are both extrinsic and intrinsic; both patient involvement and public involvement are means to an end (technocratic), and an end in themselves (empowering). Thus apart from the notion that both those paying for services – citizens– and those affected by service provision –patients– should have a right to be involved in the prioritization, design and development of health services, PPI is often linked to efforts to improve service quality and effectiveness, as well as creating accountability, legitimacy and responsiveness within a health system.

This paper draws on a comparative analysis of PPI in health policy in England, Sweden and Finland using a framework for comparative European analysis (Dent and Pahor 2015). The comparative analysis seeks to elaborate both commonalities and differences across the three countries in terms of policies that promote patient choice, co-production and patient voice. We go on to consider the tensions that arise in the analysis including the shifting of responsibility and the challenges to accountability and whether a clearer articulation of the distinction between public involvement and patient involvement resolves some of these issues.

### **'How can Anybody be Representative for Those Kind of People?' Forms of Patient Representation in Health Research, and why it is Always Contestable**

*Maguire, K., Britten, N.*  
(University of Exeter Medical School)

Different discourses that co-exist within the world of patient and public involvement in health and social care research echo a tangle of historical, social, political and theoretical roots. These range from the radical activism, born of civil rights movements, to a more passive model of patient education. This paper will explore the concept of 'representation' and the ways it is used by people serving as 'patient' or 'lay' representatives in a range of roles within research projects, funding bodies and academic institutions. Drawing on literature from social and political sciences it will question how people conceptualise their acts of representation, and how judgements are made about what can count as legitimate forms of representation. From this we propose a framework of meanings for patient and public 'representation' in health and social care research.

## Ethics

WHITEHALL 1, CAMS

**Thursday 08 September 2016 at 14:00 - 16:50**

### **Local Ethical Review of Biomedical Research Using Animals: Constructing Ethical Science**

*Job, K.*  
(Cardiff University)

Biomedical research with human subjects is often underpinned by research using non-human animals, but sociological analysis of animal research governance remains sparse. In the UK the use of animals in scientific procedures is governed by the Home Office through a three-tier licensing system under the Animals (Scientific Procedures) Act 1986, as amended. This enabling regulation provides a protected space for scientists to experiment on animals, subject to certain conditions and oversight. Since 1999, a process of ethical review at the local level has been a standard condition for all establishments licensed under this Act. Ethical review is an evolving process with locally negotiated rules defining membership structures, committee dynamics and the intricacies of remit. This paper draws on ethnographic observation of confidential ethical review committee meetings, supplemented with semi-structured interviews, to reveal the social practices and experience of 'doing ethics' within regulatory constraints.

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Rich empirical data allows a rare glimpse behind closed doors, into a novel space where scientific and ethical boundary work is enacted. This provides a socially situated understanding of how biomedical science using animals becomes constructed as ethical science through the process of ethical review.

### **How Parents Try 'Telling' Child Participants About their Research Participation: A Case Study of a National Birth Cohort Study in Japan**

*Ri, I., Suda, E., Muto, K.*  
(University of Tokyo)

As mothers prenatally give proxy consent to large-scale birth cohort studies, researchers are required to obtain informed assent or dissent from the child participants. However, little research has focused on the 'telling' process within families' daily lives, as what and how the children are told by parents will affect their future choices.

We conducted research on a national birth cohort study entitled the 'Japan Environmental Children's Study' (JECS) which will follow up on 100,000 children from the fetal stage to 13 years old. Structured interviews with 67 parents and semi-structured interviews with 14 parents were conducted in 2015. How participants would discuss with their children, the recognition of research participation, and social relationships between researchers and partners were prompted in the study.

As a result, parents' styles of telling were categorised based on their subjective risk/benefit assessment of research participation. Most evaluated that it would benefit their own children as a 'special privilege', and preferred 'empowered telling', which encourages children by providing positive identity, or 'directive telling', which persuades children to continue participating in the JECS. Meanwhile, parents who weighed the risks and burdens preferred 'non-directive telling' which respects children's intentions and choices including withdrawal.

As previous studies (Goodenough 2003; Ochieng 2015) suggest, child participants' attitudes also must be respected and investigated. We will conduct further research on grown-up children to confirm their actual 'telling' experiences and parents' influences on them as well as follow-up surveys on the parents in order to reveal parent-children interactions.

### **Exploring Re-Consent in the Changing Landscape of Longitudinal Cohort Studies**

*Street, H.*  
(University of Cambridge)

Developments in health research focus on linking health histories with a range of genomic technologies. This means that existing data can increasingly be used in new ways, and for different purposes, from those explicated in the original consent process. Thus the re-consent of existing study participants has become an important concept and practice. While there is a growing body of work around re-consent, much of this has been in the field of bioethics and pertaining to biobanks. In this paper I discuss my research with a longitudinal cohort that measures the cognitive function in people aged 65+. This paper covers the design and preliminary findings of my interview study, which explores issues of re-consent with cohort participants and staff. Longitudinal cohorts are fertile ground for looking at these issues as they are seen as an excellent source of both rich data, and well characterised potential participants for future studies.

With calls to integrate more empirical evidence into ethical analysis, there is scope for the further contribution of medical sociology to the discussion of re-consent. Therefore this paper argues more empirical evidence is needed, in particular a better understanding of participant views of re-consent when the purposes of the research change.

### **Making Research Ethics: Involving Patients and Publics**

*Doyle, E., Broer, T., Ross, E., Cunningham-Burley, S.*  
(University of Edinburgh)

It is a well-established practice for funders and ethical review boards to request evidence of patient and public involvement in study protocols, for both clinical and social science research. Amongst other activities, those engaged in PPI often provide input on defined tasks such as commenting on information leaflets and consent forms. However, in line with calls for more upstream engagement in shaping research projects, we argue that there is potential for more meaningful engagement in surfacing ethical issues in sociological research on health and illness. This presentation will focus on how we are involving patients and the public in some aspects of the research design stage for a qualitative study of cancer patienthood in the post-genomic era. Early conversations with PPI panel members have highlighted that ethical issues are at the forefront of many people's minds. In this presentation, we will discuss the innovative approach of conducting in-depth focus groups about ethics with patients, carers and the public, from a diverse range of backgrounds, to inform our submission for formal NHS ethical review as well as contribute to other aspects of the developing research project. This practice and the analysis following on from this, we suggest, has the possibility for reconceptualising ethics in a research context, as well as reconsidering the role of PPI in research more generally. It will also cast new light on the construction of (lay) expertise in the context of social science and clinical research.

### **Clinical Trials, Ethical Approval and Pandemics: A Sociological Investigation**

*Sukumar, P., Moore, R., Turner, J., Nichol, A.*  
(University College Dublin)

The paper will discuss important sociological issues that imping on effective clinical research. Within biomedicine clinical trials are the accepted gold standard for obtaining scientific evidence for the use of treatments and medicines. The timely initiation of such trials is considered an important first response strategy in public health emergencies such as epidemic/pandemic outbreaks. This is considered especially important since we are witnessing the emergence of several new strains of infectious diseases as well as the re-emergence many old infections.

Sociological commentary points up the restrictive and potentially coercive aspect of public health measure in response to disease outbreaks. However other social science literature points to the need for social scientists to be at the heart of such discussions and research.

Studies conducted among clinical researchers revealed that obtaining ethical and regulatory approvals are the major hindrances they see rapidly setting up clinical studies during public health emergencies. Therefore, within the European context, (as a model) it is important to understand the variation in ethical approval timelines between member states and its determinants and to look to the sociological aspects that give rise to such variations in order to develop better health research strategies for pandemic preparedness.

This paper presents some preliminary findings from an EU wide study to see how the timelines vary between countries and factors that are important in determining these variations. This research is part of a major EU wide project PREPARE (<http://www.prepare-europe.eu/>) funded by the European Commission.

## **Experiences of Health and Illness** **G63, MAIN BUILDING**

**Thursday 08 September 2016 at 14:00 - 16:15**

### **From the Damaged Body to the Body to be Repaired. An Analysis of Patient Complaints for Medical Injury**

*Winance, M., Barbot, J., Parizot I.*  
(Université Paris)

In our presentation, we focus on the body's status in the complaints that patients filed with a compensation agency. We analyze the way in which those complainants perceive and describe their body damaged by the care and consider how it might be repaired in the legal procedures. This study is based on a corpus of written complaints (N=60) filed with the French out-of-court settlement mechanism. An inductive analysis was conducted based on the coding of extracts in which people talk about their bodies and their expectations about compensation of their damage, the identification of pertinent contrasts, and the construction of transversal categories. We analyze the way in which the patients describe their damaged body, using the notion of loss. We approach this as a 'loss of self', in reference to the sociology of illness. We show that these losses can also be of another type. Drawing on Science and Technology Studies, we highlight the manner in which patients approach their losses as 'losses in practice'. These losses are defined by the patients putting forward the concrete experience of a body harmed by the treatment received, and by their formulation of expectations in terms of compensation. We highlight four ways in which the reality of the damaged body is given a form in terms of expectations of repair: the 'body-producer', the 'body-ecological', the 'body-help' and the 'body-self-image'. This analysis allow us to contribute to works relating to the status of patients' bodily experiences during care and works on patient complaints.

### **'I Still Feel Like I Am An Unexploded Bomb'. The Impact and Understandings of Chest Pain**

*Cramer, H., Johnson, R., Carsen, A., Horwood, J., Kessler, D., McManus, R., Rodgers, A., Feder, G.*  
(University of Bristol)

Chest pain causes anxiety for patients and clinicians alike. However, it is unclear how people understand chest pain and whether attending a rapid chest pain clinic is sufficiently reassuring. This study took a qualitative longitudinal approach. It involved observations in UK clinics, interviews with GPs and chest pain clinicians, repeat in-depth interviews with 24 chest pain sufferers (with and without a cardiac diagnosis) and visual representations of chest pain experiences. Emerging findings show a wide variety of understandings and responses to chest pain and subsequent treatment. Some people were reassured by their consultation with a chest pain clinician or viewed the incident(s) as an opportunity to self-reflect and make lifestyle changes. Many of those who were sent away with an explanation that their chest pain was unlikely to be of cardiac origin, said they were not fully reassured and some continued to use accident and emergency services when further chest pain occurred. Some of those referred for further cardiac testing were extremely unsettled by the extended period of uncertainty whereas others were very accepting, even if a positive cardiac diagnosis was reached. Fears about repeating a kinship pattern of heart problems loomed large in more

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public clinical narratives. This concern was reinforced by clinicians enquiring keenly into family histories of heart disease. In more private accounts elicited in research interviews, past trauma and loss of kinship relations in ways other than by heart disease (e.g. suicide) framed the current chest pain episode.

### **Ghost Stories: The Narrative Construction of Phantom Limb Sensations by Lower-Limb Amputees**

*Heavey, E.*  
(University of York)

Medical and social understandings of phantom limb sensation (PLS) have changed radically in the past hundred years, from the ghastly evidence of a fractured psyche, to useful – though still mysterious – neurologic processes. Recently, philosophers like Sobchack have used phenomenological approaches to reveal the lived experiences of phantoms. However, despite the growing field of narrative medicine and interest in patients' stories, there has been no exploration of individuals' narrative constructions of PLS. Drawing on Crawford's recent exploration of the sociomedical history of PLS, and its implications for people who experience phantoms, I analyse video data of interviews with lower-limb amputees to demonstrate how storytelling is used to construct PLS (or the absence thereof), and the implications of analysing such constructions.

Using an interactional narrative analytic approach, I show how storytellers construct versions of their own subjectively lived embodiment, whilst simultaneously constructing a competent self and dismissing the possibility of psychic damage or delusion. To achieve this complex rhetorical task, storytellers draw on (1) their past experience of which I have no knowledge; (2) assumptions about our shared knowledge of embodiment (e.g. my experiences of non-phantom pain); (3) the shared space in the moment of storytelling (e.g. through non-verbal performance and deixis). By analysing stories like these, we can extend narrative medicine to include experiences of ghostly bodies, and begin to understand how shared discourses about phantoms are experienced and addressed by those who experience PLS, and the challenges faced when accounting for these experience in social or medical contexts.

### **Focused Ethnography with Refugees and Asylum Seekers from Sub Saharan Africa in Glasgow: Exploring Perceptions of Health and Wellbeing and Experiences of Health Service Utilisation**

*Isaacs, A., Burns, N., Macdonald, S., O'Donnell, C.*  
(University of Glasgow)

Glasgow's population is growing in ethnic diversity, driven in part by increasing numbers of migrants, refugees and asylum seekers. This presents new challenges for the health care system, which must meet the needs of individuals from diverse backgrounds with a wide range of needs and potential vulnerabilities. I conducted a focused ethnography with refugees and asylum seekers from Sub-Saharan Africa in Glasgow, to explore i) what it means to keep healthy and ii) their experiences of healthcare utilisation. A range of methods informed by ethnographic and participatory approaches were utilised including engagement with community groups, mind mapping, 'go-along' interviews, and formal interviews. Thematic analysis was conducted in conjunction with the theoretical framework of 'candidacy' (Dixon Woods et al 2006), which explores healthcare access for vulnerable groups, and theoretical perspectives from critical medical anthropology that consider the structural determinants of health outcomes. Participants were broadly positive about accessing healthcare in Glasgow. They emphasised maintaining good health through diet, exercise, keeping clean and establishing social connections. However, many felt unable to lead healthy lives or engage in healthy 'behaviours' due to wider structural factors associated with the UK asylum system including poverty, insecurity and lack of a sense of safety. The experience of seeking asylum in the UK has a deleterious and long-lasting effect on individuals' capacity to keep healthy and engage in health services. To create fully inclusive services, efforts to promote health and improve care access must take into account all potential sites of vulnerability to ill health.

## **Health Care Organisations** **STEELHOUSE 3, CAMS**

**Thursday 08 September 2016 at 15:45 - 16:15**

### **Neither Admitted nor Discharged: The Rise and Functions of 'Observation Units' in the United States and England**

*Martin, G.*  
(University of Leicester)

Observation units are increasingly used to provide care for patients attending the emergency department, for whom a decision about whether to admit or discharge cannot immediately be made. Evidence highlights the benefits of observation status for a defined group of patients for whom extended diagnostic or therapeutic pathways apply. However, use of observation units has also been driven by other concerns, including pressures to maximise hospital

reimbursement in the US, and the four-hour emergency department standard in England. This has led commentators to highlight the risks of observation for patients, who may be left in 'clinical limbo', with potential adverse consequences for patient safety and (in the US) extra out-of-pocket expense.

Our comparative study of observation units in the US and England examined how emergency physicians decide to admit, discharge or observe. Through 24 qualitative interviews in three hospitals, we sought to surface the frameworks deployed by physicians in deciding on patient pathways, including the influence of non-clinical considerations on these frameworks. Our study highlights a misalignment between the clear-cut bureaucratic designations put forward in policy on observation units, and the messier clinical realities that render straightforward distinctions between appropriate and inappropriate use of observation—and between clinical and non-clinical rationales—problematic. We highlight in particular an important but previously undocumented use for observation units, which reflects neither the protocol-based pathways described by advocates nor the badge of organisational convenience noted by critics—but which physicians saw as crucial to observation units' contribution to both high-quality care and patient flow.

## Lifecourse STEELHOUSE 2, CAMS

**Thursday 08 September 2016 at 14:00 - 15:40**

### **Active Ageing and the 'Busyness' Ethic: Findings from a Qualitative Study of Life in Retirement in the West of Scotland**

*McCormack, F., Edgar, F., Seaman, P., Bell, K., Gilhooly, M., Duffy, T., Nicholson, D.*  
(University of the West of Scotland)

The purpose of this paper is to present findings from a study of life in retirement which explores the concept of active ageing. In the context of a demographic shift and a 'greying' population a new discourse has emerged in public health that focuses on the risks and challenges of ageing (see for example Scottish Executive, 2007; WHO, 2002). Two closely connected discourses, 'healthy ageing' and 'active ageing', have become central goals of public health policy representing new ways of disciplining older people's bodies (Katz 2000; Ekerdt 1986).

Our analysis of data drawn from qualitative interviews with older people about the routines, social networks, activities and pursuits that make up their lives suggests that a fear of inactivity and a 'busyness' ethic has become a significant focus in the lives of many older people. Whilst this may produce positive outcomes for health, there is a danger of stigmatising older people's lives in a way that can act against positive health outcomes and reduce quality of life.

The data presented is drawn from in-depth semi-structured interviews with 40 retired men and women aged between 55 and 79. Participants were recruited via general practitioners and local community groups. A sampling framework based on gender, age and levels of deprivation (measured using the Scottish index of Multiple Deprivation) was used to ensure the inclusion of a broad range of experiences. Data was analysed using a phenomenological approach, applying Braun and Clark's thematic analysis, and full ethical approval was granted.

### **Resisting Narratives of Decline, Constructing Healthy, Capable and Active Selves Through Narratives of Place Making with Aging**

*Pack, R., Hand, C., Laliberte Rudman, D., Huot, S., Gilliland, J.*  
(University of Western Ontario)

Within the context of the aging population, aging has become a central focus of sociological inquiry in recent years. Critical sociological studies of aging have challenged the master narratives of decline, isolation and invisibility, and the neoliberally inflected narrative of 'positive aging' that individualizes the responsibility to age well through defying aging via particular forms of activity. Such studies have highlighted the diverse ways in which older adults participate in community life and create a sense of connectedness through various forms of activity, and how such participation is contextually shaped. Social connectedness has been positioned as an important factor that can affect the health and well-being of older adults. While previous research reveals much about experiences of social connectedness and insights as to how place may relate to these experiences, an explicit focus on the physical and social 'place' of neighbourhoods is lacking—arguably a key part of understanding the continuum of isolation to inclusion.

This paper presents preliminary results drawn from an interdisciplinary study that combines mapping and narrative inquiry approaches to explore how neighbourhood and person transact to shape a sense of social connectedness in older adults. This paper focuses specifically on how older women resist the master narrative of decline, and construct themselves as capable, active and healthy subjects through narratives of their interaction with/in their neighbourhoods and place. In particular, this paper explores narrative strategies that women employ to construct themselves as 'in control' of their aging bodies while resisting negative images of 'oldness' and decline.

# Mental Health STAFFORD 2, CAMS

Thursday 08 September 2016 at 14:00 - 16:15

### **Hysteresis, Social Congestion and Debt: Towards a Sociology of Mental Health Disorders in Undergraduates**

*Cant, S.*

*(Canterbury Christ Church University)*

The expansion of mass higher education during the last twenty years in the UK has been mirrored by a concomitant rise in the number of undergraduate students exhibiting psycho-pathological symptoms. In a response to the dearth of sociological work in this area and drawing on the sociologies of higher education and health and illness, the paper maps a framework for understanding the rise of mental health disorders in the undergraduate population. In doing so, I draw a connection between broader social and cultural change and individual psychological malaise. Widening participation has simultaneously extended educational opportunities but also, I argue, provided the context for a state of hysteresis (Bourdieu 1980) to emerge – a possible gap between the 'habitus' of the student and the expectations of the academic 'field' - with potential pathological consequences. Moreover, the increase in student numbers have necessarily increased social competition for university places and produced social congestion in the workplace. The promises of higher education are no longer accessible to all and, when coupled with the burden of financial debt resultant from changes to the funding regime, the context for the elevation of levels of anxiety and depression is established. These potential threats to emotional wellbeing serve to question the normative view that higher education is straightforwardly beneficial instead suggesting that university study can now have a psychological as well as an economic price.

### **Positive Mental Health and Mortality**

*Jacobi, C.*

*(University of Oxford)*

This study examines the association between positive mental health (PMH) and all-cause mortality in a nationally-representative sample of the United Kingdom via the new Warwick-Edinburgh-Mental-Well-Being-Scale (WEMWBS). The WEMWBS combines emotional, psychological and subjective well-being into an integrated PMH measure. The coherence and usefulness of the WEMWBS as an indicator of PMH is tested by comparing and contrasting it to an established measure of negative mental health (NMH), the GHQ, and to a unidimensional measure of cognitive mental health, life satisfaction. Discrete-time survival models (complementary log-log) are used to analyse if PMH is associated with a lower risk of mortality over a 4-year follow-up period (N=28,662), when adjusting for chronic health conditions and common sociodemographic factors. The results indicate that better PMH has a strongly protective effect against mortality (HR 0.82, 95% confidence interval: 0.76-0.89, P<0.001). PMH appears to be somewhat orthogonal to negative mental health and to be relatively distinct from life-satisfaction. Overall, the reported associations between the WEMWBS and mortality support the notion that an integrated PMH approach can provide new insights. The results are supportive of a dual-continua mental health model (Keyes 2002). Further research is needed to specify the exact pathways between the different dimensions of PMH and mortality.

### **Frames Of Recognition: Lessons to be Learnt for Professionals from Informal Adult Support Experienced by Children of Parents with Alcohol Problems?**

*Werner, A., Malterud, K.*

*(Health Services Research Unit)*

Several studies show that alcohol problems put heavy strain on families and children and that such an effect may be long-term. Children growing up under these conditions often conceal their problems. However, they also report experiences of informal support as essential. Still, not much is known about what professionals can learn and pursue from the support experiences from informal caregivers in commonplace contexts. Based on semi-structured interviews with adults who grew up with parental alcohol problems recruited from treatment clinics in Oslo/Norway, we explored the help they were offered during childhood and adolescence, and how they experienced that their needs were met. Data were analysed with systematic text condensation, a method for thematic cross-case analysis. In spite of obvious needs, the participants had not received professional help during their upbringing. They described the feeling of being betrayed by professionals and adults who never asked about their situation or responded to their needs. Still, they also recalled significant situations with adults, who had provided safety, protection and normality in everyday life during childhood and adolescence. Goffman's frame analysis may offer a lens to study how supportive situations were defined and to understand opportunities and limitations for translation of lay social interaction to professional encounters.

## Methods

### STAFFORD 1, CAMS

**Thursday 08 September 2016 at 14:00 - 14:30**

#### **The Use of Documents in Ethnography: Understanding a Patient's Journey Through Multiple Sources**

*Grant, A.*  
(Cardiff University)

Examination of pre-existing documents has been a largely neglected element within ethnographic studies (Atkinson & Coffey, 2010). If they are critically evaluated, however, for example analysis of the purpose and intended audience of the document, and other institutional constraints (Scott, 2006), documents can add a further layer of detail to ethnographic insights which may contrast with observed or reported accounts of events.

As part of research into an NHS patient management service for chronic conditions (the Condition Management Project), an ethnographic approach was adopted, following staff from the process of referral, to participation and discharge. Although permission was granted to observe treatment, it was decided not to observe, due to the high likelihood of negative outcomes for participants (eg: disengagement with the service). As such, I examined patient records alongside narrative life history interviews with patients.

The use of multiple sources of data (interviews with patients, staff and documents) provided a richer understanding of the complicated issues of disability, work and identity, than either method could have produced in isolation. In this paper, I draw specifically on data relating to one research participant, in which notions of disability, respectability, citizenship and pain were described differently in the interview data and the patient file. I conclude that, wherever possible, ethnographic researchers should consider the use of documents alongside observations and interviews.

## Patient - Professional Interaction

### WHITEHALL 3, CAMS

**Thursday 08 September 2016 at 14:00 - 16:50**

#### **Frames of Mental Health**

*Rondelez, E., Vandekinderen, C., Roets, G., Rutten, K., Bracke, P., Bracke, S.*  
(Ghent University, Research group HEDERA)

The mental health of Muslims with a migration background in Belgium seems to be particularly at risk, yet their underrepresentation is observed in mental health care. We therefore assert that we are confronted with a conundrum, which entails a set of questions: why do Muslims with a migration background not find their way to mental health care services, and where do they take their mental health concerns? And if they find their way, how do their contacts with established mental health services look like? In this presentation, we try to explore these questions from the perspective of professionals in mental health care services, as their attitudes play a role on accessibility of mental health care for Muslims with a migration background.

In an attempt to gain a more in-depth understanding of the dynamics at play in this conundrum, we are inspired by the work of Goffman to explore 'frames' that are used by professionals when they approach migrants with a migration background in their practices.

Methodologically, we draw on a qualitative interpretative study with the intention to map social problem constructions in the field of mental health care in the city of Ghent (Belgium). We used semi-structured qualitative interviews that enabled us to figure out the frames that local actors in mental health care use to give meaning to their experiences with Muslims with a migration background.

As such, we hope to contribute to the medical sociological knowledge about Muslims with a migration background in relation to mental health care.

#### **'You Have to Step Back and Ask: Why Isn't it Flowing?' Perspectives from Recent Migrants and Health Professionals on Communication in Primary Care**

*Lindenmeyer, A., Redwood, S., Adams, R., Phillimore, J.*  
(University of Birmingham)

More migrants are arriving from more places, to more places in the UK, than ever before, many encountering a primary care service for the first time. We conducted two qualitative studies exploring how superdiverse (Vertovec,

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2007) new migrants access health services in the UK, and the ways in which primary care professionals (PCPs) are providing care. For the first study, community researchers recruited 23 migrants (from a range of countries e.g. Iran, Poland, Zimbabwe) and interviewed them in their chosen language; for the second, we interviewed 19 PCPs from 10 practices. A comparative thematic analysis of narrated interactions from both studies indicated that while there were overt misunderstandings caused by differences in language or vocabulary, both migrants and health professionals talked about a communicative disjoint. PCPs worried whether patients who sought to communicate in English understood what had been discussed; migrants felt that PCPs' decisions e.g. on prescriptions were not explained to them and some felt their health problems were not taken seriously. PCPs developed strategies to reach out (e.g. by greeting the patient in their own language) and to pick up misunderstandings at subsequent consultations. We used Spencer-Oatey's (2000) model of intercultural rapport to interpret these interactions. For example patients' need to present themselves as competent could mean that they did not ask questions, while different understandings of 'association rights' i.e. how much interaction to expect, could result in patients feeling dissatisfied. Understanding these interaction patterns could help explain miscommunication and suggest ways to overcome it.

### **Patients' Experience of Continuity of Care in Hospital Care: The Case of Hospital Discharge**

*Corrigan, O., Georgiadis, A.*  
(Healthwatch Essex)

Continuity of care is an essential attribute of healthcare that aims at promoting seamless patient care over the duration and as patients move from one care provider to another. In this chapter we examine how patients experience continuity of care in relation to discharge planning and when they transition from hospital care to self-care. Firstly, we demonstrate that a theoretical framework centred on Goffman's dramaturgical approach can help us elucidate the effects of personal, professional, and organisational factors to patients' experience of continuity of care. Secondly, we explore the utility of the framework by applying it to the semi-structured interview and audio diary data that we collected from patients between June 2015 and December 2015. Following Goffman, we employ the concepts 'frontstage' and 'backstage' to illustrate which and how the sub-types of continuity affected patients' experience of hospital discharge and care transition. Whereas management and informational continuity (backstage) were the most essential sub-types of care continuity for patients to experience their overall care as connected and coherent, relational continuity (frontstage) was not reported as important. Goffman's dramaturgical approach was a useful framework to explore how the different types of continuity of care relate to patients' experience of discharge planning and care transition. Further research is required to better understand the concept of continuity of care in hospital care, and which of its sub-types are important to patients when they transition between different levels and/or locations of care.

### **Patient Expectation, Experience, and Satisfaction with Musculoskeletal Physiotherapy**

*Loughran, I., Adams, N., Caplan, N.*  
(Northumbria University)

Musculoskeletal conditions are highly prevalent across the population, and in particular across the working age population. They account for a significant burden on the health care systems and a significant cost to the wider economy. Physiotherapy is one of the first line treatments for most common musculoskeletal conditions. Patient experience and satisfaction with treatment is thought to be an indicator of compliance with treatment. There has been little work to date to investigate patient experience with physiotherapy treatment for musculoskeletal conditions.

A three phase approach was designed, with each phase building on the previous work. A systematic review and narrative analysis was undertaken to examine existing literature. Then, a series of patient interviews were undertaken to test the experiences of patients who had physiotherapy against the wider literature. A questionnaire was then developed and piloted as a method of studying a wider range of patients who had received physiotherapy.

The systematic review found most existing measures were non UK based and undertaken in varied healthcare environments so not immediately applicable to the UK. The concept of satisfaction is not clearly defined and therefore not easy to measure. Patients experience appears related to interpersonal factors rather than service factors.

Service developments can be based on the assessment of patient experience, which is an independent variable. Basing developments on patients reported experiences should improve services and make them more patient focused, which is the high level policy aim of the NHS.

### **Feeling 'Dismissed' and Imposed Consumerism: Accounts of Patient-Professional Interactions from People with Multiple Sclerosis**

*Eccles, A., Ryan, S., Locock, L., Ziebland, S.*  
(University of Oxford)

BACKGROUND: Recent decades have seen the promotion of patient involvement during healthcare interactions. There has been a paradigm shift where the concept of 'shared decision making' (SDM) has been advocated. During

SDM patients and clinicians both bring expertise to the consultation, working in equal partnership to decide the best course of action. Multiple Sclerosis (MS) is a highly heterogeneous neurological degenerative condition, for which there is no cure and treatments available have limited effectiveness. In this setting people with MS face uncertain treatment decisions.

**METHODS:** 22 in-depth semi-structured qualitative interviews were carried out with people with MS across the UK in order to explore experiences of decision making and their accounts of interactions with clinicians. These interviews were thematically analysed using a modified grounded theory approach.

**RESULTS:** When facing decisions about which DMD to start, participants typically found that they were given lots of information, but no advice from neurologists and they made such decisions independently. This often came as a shock to participants who felt unprepared, unsupported and would have liked more guidance. In the archetypal consumerist interactions, patients have high levels of decisional power and clinicians have low, as patients independently make decisions and use clinicians as information sources. On a surface level, this set-up is present in participants' accounts about DMD decisions. However, it is more of an 'imposed consumerism', as accounts suggest that people with MS typically did not opt for this style of interaction but felt it had been imposed upon them.

## Risk WHITEHALL 2, CAMS

**Thursday 08 September 2016 at 14:00 - 15:40**

### **Uncertain Futures: Governing Women Through Constructions of 'Risky' Survivorship**

*Pack, R.*

*(University of Western Ontario)*

Departing from research on breast cancer experience and treatment, breast cancer survivorship has emerged as a focus of sociological inquiry in the last twenty years. Thus far, most critical sociological research into breast cancer survivorship has examined popular texts, women's autobiographical writings, women's lived experiences and breast cancer specific fundraising organizations. Little research has focused on how breast cancer survivorship is constructed and constituted in professional and biomedical discursive fields. As the number of breast cancer survivors continues to increase, and more women are incorporated into biomedicalized survivorship care programs, survivorship is emerging as a domain of professional practice and expertise.

The Springer Journal of Cancer Survivorship, first published in 2007, is the first, and currently only, academic journal that takes cancer survivorship as its organizing principle. This journal provides a unique opportunity to examine how discourses of breast cancer survivorship are constructed, and towards what ends they are mobilized, within this new sub-set of knowledge production. Informed by governmentality and feminist theory, this paper will explore how women's bodies are governed, and highlight how risk discourse is mobilized to produce new possibilities for intervention and novel forms of biomedicalized citizen-subjects. Specifically, drawing from an in-depth critical discourse analysis, this paper will explore how breast cancer survivorship is constructed as a unique and chronic (risk) condition that is distinct from cancer and that requires life-long management and surveillance.

### **Representations of Ageing as a Risk Factor for Cancer in UK Newspapers**

*Cunningham, Y., MacDonald, S., Robb, K., MacLeod, U., Anker, T., Hilton, S.*

*(Institute of Health and Wellbeing)*

We're all getting older and more of us are getting cancer. Ten million people in the UK are over 65 years old, by 2033 it's estimated that that figure will reach 15.5 million, by 2050 it'll be 19 million. Cancer diagnoses continue to rise with longer life expectancy—in the UK three-quarters of all cancers are diagnosed in those over 60 and a third in those over 75.

Cancer is, as all diseases are, recognised and experienced within a social and cultural context, and how people understand and act on cancer information is often mediated and amplified through mass media. Given the importance of age as a risk factor, and the media's role in shaping public understandings and health behaviours, this project examines how cancer and ageing is represented in media, to better understand how it impacts on older adults' cancer knowledge and help-seeking behaviour. Our content analysis of UK newspapers showed that age was mentioned less than other risk factors for cancer, and that the celebrities and 'ordinary people' with cancer represented in newspaper stories were younger than people with cancer in the UK population.

General representations of people in media are younger, this work shows that this holds true even in cancer stories, where older adults are most at risk. Public policy and community programmes need to be developed to effectively address this problem. Stakeholders (including cancer research organisations and charities and representative groups for older people) need to develop effective strategies to use the media.

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### **Where's the Fun? The Absence of Pleasure in Discourses about Sex for Young People**

*Brown, S.*  
(Edinburgh Napier University)

Discussions about young people's sexual health often focus on negative, 'risky' aspects of sex: sexually transmitted infections, coercive or regretted sex, unwanted conceptions, teenage pregnancies. Despite a substantial body of research literature on sexual pleasure, it is rarely mentioned in health promotion material aimed at young people, which often focuses on negative outcomes of sexual behaviour, and how to minimise or avoid risk. The individualising of risk ignores the social contexts within which young people operate and make decisions about sex, as well as presenting contexts which are overwhelmingly heteronormative.

In this conceptual paper I draw on Foucault's work on governmentality and power relations in arguing that absence of a discourse of pleasure makes it more difficult for young people to talk about sex with their partner and to have safer sex; it also renders them ill-equipped to resist coercive sex or other unwanted encounters. In addition, an emphasis on danger, risk and protection rather than rights and pleasure reinforces gender inequalities. This is not to argue that information is unnecessary; clearly, people need to be able to protect themselves from STIs and avoid unwanted pregnancies. However, my main contention is that a focus on risks and problems, and avoiding talking about sex as pleasurable and fun, makes it difficult for young people to negotiate sex lives that are not only healthy and safe, but also pleasurable.

## **STS and Medicine**

### **BYNG KENDRICK - G11, MAIN BUILDING**

**Thursday 08 September 2016 at 15:45 - 17:25**

### **Non-Invasive Prenatal Testing/Diagnosis (NIPT): How Genomic Technologies Assembled and Reassembled from the Laboratory to the Clinic Intensify Possibilities for Reshaping Society**

*Strange, H., Latimer, J.*  
(Cardiff University)

This paper explores how emergent reproductive technologies align clinical practices and the new genetics in the production of culturally significant classificatory forms. Drawing on a study of non-invasive prenatal testing/diagnosis (NIPT) the paper shows how practices of division and categorisation contribute to the shaping of discourses and practices around exactly what, and who, is perceived as being 'normal', 'benign' or 'desirable', and by extension, what and who becomes constructed as 'abnormal', 'pathological' and 'undesirable'. We hold our analysis against earlier studies of clinical genetics, especially dysmorphology (Latimer 2013), in order to raise questions over how the emergence of novel genomic technologies, as well as the everyday practices of clinical genetics, assemble new classificatory, categorical and divisive structures. In turn, we show how the various discourses that such processes draw upon and contribute to, raise problematic and contentious issues around the construction of 'normal' pregnancies, disabilities, and (healthy) lives.

Methodological approach

As part of her PhD research, Heather conducted an in-depth qualitative study of the emergence and early clinical translation of NIPT, interviewing clinicians, policy makers, scientists, patients and parents about their experiences and understandings of this new and rapidly evolving reproductive technology. Examining interview data alongside scientific publications, advertising material and media reports, her work demonstrates how questions regarding the biopolitical power of routine screening, its influence on categories of 'choice, and the categorisation of 'normal' and 'abnormal' ideas of pregnancy, life and disease, are repeatedly raised in connection with NIPT.

### **Reflections on Contemporary Patienthood: Post-Genomic Cancer and 4P Medicine**

*Cunningham-Burley, S., Broer, T., Ross, E., Kerr, E. A.*  
(University of Edinburgh)

Oncology is at the forefront of the evolution of personalised medicine. Rhetorically, patients are at the centre of the emergent health care paradigm of 'predictive, personalised, preventive and participatory' medicine; pragmatically, multiple types of data from patients, whether sick or well, are essential for researchers, clinicians and patients in identifying and delivering 'actionable possibilities' (Hood et al, 2015). This paper has two aims: to explore how patients are fashioned as active participants in shaping post-genomic cancer medicine; and, to explore how patienthood is being transformed as cancer itself comes to be understood and attended to differently.

We draw on two sources of data to develop our analysis. First, we interrogate the clinical, scientific and social scientific literature that reviews and comments on the practices of predictive, personalised, preventive and

participatory medicine in relation to cancer and analyse the place of patients within this. In particular, we explore how the concept of partnership is constructed in the context of novel research methodologies, within, for example, clinical trials relating to cancer. Second, we present an analysis of in-depth interviews with cancer scientists, clinicians, other practitioners and interested publics, conducted in the UK. We consider how those engaged in research projects and clinical practices involve patients, in what ways and with what effects. Finally, we consider how social and ethical issues in relation to personalised and predictive medicine are articulated. We contribute to debates on the role, place and configuration of patienthood in contemporary technomedicine, and to the sociology of knowledge more widely.

### **Multiplying Gateways for Adoption of Regenerative Medicine**

*Faulkner, A.*

*(University of Sussex)*

The paper poses the question of the extent to which there are emerging flexibilities in existing and developing gatekeeping regimes applicable to regenerative medicine products. It addresses these questions in the context of recent developments in the UK and its European Union regulatory and reimbursement/payment contexts. The concepts of 'gatekeeping' and 'gateways' are developed to point to the ways in which regulatory institutions, health technology assessment (HTA) organisations, and national planners and purchasers of health services define and control passage points of entry to the medical product marketplace and to the adoption of products into the public healthcare system. Drawing on a wide set of recent policy documents, it is argued that the measures promoted in policy developments such as conditional authorisation, compassionate use exemptions, 'promising innovative' regulatory designations, parallel review by market regulators and HTA procedures, and 'risk-sharing' payment schemes illustrate a range of flexibilities and alternative gateways which are being constructed around central, legal restrictive gatekeeping regimes. The paper then considers: first, whether the proliferation of these developments can be considered 'experimentalist', participative governance or 'regulatory capture'; second, whether the apparent flexibilities achieve the goals of industry, patient groups and regulators; and third to what extent public health is promoted. The concepts of gatekeeping and gateways enable some understanding of these 'hybrid' developments, as the arenas of market regulation, health technology assessment and healthcare system planning are being drawn closer together in the UK, EU and other innovating biomedical health systems globally.



## Citizenship and Health STAFFORD 2, CAMS

**Friday 09 September 2016 at 11:55 - 12:25**

### Contingents in the Art of Giving

*Mahon-Daly, P.*  
(Buckinghamshire New University)

Body and Donation Giving to Get back – contingencies in the Art of giving

Another way of understanding the rationale for giving blood is by extrapolating the concept of contingent donation rather than altruistic donation. Many donors, in this study only give to get back a similar safe donation should they or their family need it. This idea is linked to the role of the family as both the reason for giving and for whom the donations were intended. This is a departure from the giving to strangers paradigm embedded in early work on blood donation. This paper is concerned with reporting the changes for whom donors give their blood, who they would like to benefit from it and who they would not like to benefit from their probity.

The most significant finding from the data has been related to the notions of citizenship, both at the inception of the blood donor service and in contrasting the contemporary ideas surrounding the active citizen. The role of the blood donor has been highlighted to embody the changed notions and roles and responsibilities concerning active citizenship in the way the donors understand the personal constraints and privations required to ensure a safe donated blood pool in modern Britain. The changes that have taken place in recent years in Britain in the donor world highlight concern for good citizenship, control and management of the donor body, and the management and exclusion of risk laden sections of society.

## Complementary and Alternative Medicines STEELHOUSE 3, CAMS

**Friday 09 September 2016 at 10:10 - 11:15**

### The Institutionalisation of Medical Knowledge (The Case of CAM)

*Lytovka, M.*  
(Maria Curie-Skłodowska University)

Over the last three decades, many European countries have been involved in the dynamic process of 'camisation', the institutionalization of CAM in healthcare and applying CAM treatments and solutions in everyday life. This process has been challenging the prevailing healthcare systems and changing relationship between CAM and the state having the potential to reverse the direction of medicalisation and to encourage demedicalisation. Fundamentally, CAM practitioners started promoting alternative methods of healing when biomedicine's tenets began to be questioned. At the same time, clinical pragmatism, growth of iatrogenic diseases, anti-aging movement, prevention, and holism have been significant conceptual resources used by CAM practitioners to seek legitimacy within healthcare. These fundamental reasons for 'camisation' of European health care systems, as well as the consequences of this process, will be discussed in this paper.

### The Legacy of Dr Zomb. Public Perceptions of Hypnotherapy

*Krouwel, M., Jolly, P., Greenfield, S.*  
(University of Birmingham)

Hypnotherapy appeared in National Institute of Clinical Excellence (NICE) guidelines in 2008 (NICE CG61) for the treatment of Refractory Irritable Bowel Syndrome (IBS). Although it appears to enjoy the support of Clinicians (Cox, De Lusignan & Chan 2004), hypnotherapy does not appear to be broadly popular with the public (Hunt et al 2010). Media stereotypes can be strongly influential on health behaviours (Seale, 2003). A possible cause for the public's apparent disinterest in hypnotherapy may be distrust fed by media imagery (Conn 1981). The media portrayal of hypnosis includes everything from; hypnotically predatory snakes (Jungle book), evil vizier's (Alladin), mind control (The Manchurian Candidate), and is even a game show device (You're back in the room). In addition, visual presentations of the hypnotist, frequently replete with pocket watch and neo-magical hand gestures serve to create a sense of liminality around the figure.

This paper uses literature from a systematic review which sought to identify the general public's perception of hypnotherapy / hypnosis. It will discuss; what people understand by the state and phenomena of hypnosis; what

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people understand by the concept of 'Hypnotisability'; Do people have preferences with regard to who conducts hypnotherapy and where; Do certain patient groups have differing perceptions of hypnotherapy? A broad understanding of the general public's perception of hypnotherapy and the contribution of media stereotypes to this would provide valuable information for any health service considering offering hypnotherapeutic services, in an effort to gain an understanding of what are people's feelings about Hypnotherapy.

# Critical Public Health

STEELHOUSE 2, CAMS

Friday 09 September 2016 at 09:00 - 12:25

### The Pleasures and Perils of Everyday Eating in Sociological Context

*Bissell, P., Peacock, M.*  
(University of Sheffield)

In this presentation, we reflect on one of the ironies of the increasingly diverse sociology of food and eating as it manifests across the developed world, seeking to foreground what seems to us an increasingly important issue - the lack of empirical, sociologically informed studies exploring how food and eating link with pleasure and displeasure. That this should be the case is particularly interesting in a policy and public health context which focuses on the multi-faceted problem of obesity and overweight. Here, we present data from a recent qualitative study amongst people characterised as obese to shed more light on how people talked about the embodied pleasures (and displeasures) of food and eating. We describe some of the affective dimensions associated with eating in the context of obesity (pleasure, greed, shame and disgust) and the anxieties and responses associated with it. We draw in particular on Elspeth Probyn's and Lauren Berlant's reflections on food and eating and seek to link the experience of shame and obesity to contemporary neoliberal discourses which emphasise the role of personal responsibility above all else. We suggest that researchers should pay more attention to developing an embodied sociology of pleasure in seeking to explain the 'problem' of obesity in the developed world.

### Nutrition Justice: Policy, Parents and Child Fatness

*Noonan-Gunning, S.*  
(City University)

It is argued child obesity in contemporary times is a product of modern capitalism - a multifactorial problem including social gradient in England.

With background concern for child health, individualising and responsabilising policy discourses place greatest burden on poorest parents. This is bound within deficit model. Whilst parents' food practices are under the microscope, there is little research about their policy experiences and solutions.

Drawn from my PhD this paper focuses on the views of predominantly working class parents, with children, medically described as obese. The PhD, a critical policy analysis, within the local state, explores the meanings of social class in context of food-related obesity policy. Fieldwork included thirty-two interviews with policy makers and recipients. Theoretically it draws on Critical Theory and Marxism.

Hegemonic processes arise within policy producing stigma and division that penetrate community and family life. Social marketing and NCMP letters are implicated. In the context of governmentality, health anxiety is used as parents take 'ultimate responsibility'. Government gives the 'impression' of helping. At the same time food companies are 'allowed' to sell unhealthy foods that saturate poor communities. There is strong sense of nutritional injustice around children's foods and poor health: 'we don't cost anything, when they bury us'. In the context of democracy deficit parents believe they should inform policy. Parents articulate policy changes: universalism in child health, collectivism at community level, broad reforms of food system, distribution and employment rights. New policy direction is needed.

### Assumed, Shared Food Narratives in the Context of Motive Talk about Food Practices

*Bissell, P., Peacock, M.*  
(University of Sheffield)

In this presentation, we introduce assumed, shared food narratives (ASFN) as a novel way of interpreting how actors provide accounts about 'motive talk' in relation to food practices, drawing on data from two qualitative studies, one conducted in Nottingham, the other in Doncaster, England. We extend Monaghan's (2008) re-working of Scott and Lynam's (1968) classic typology of accounts (encompassing excuses and justifications alongside contrition and

repudiation), to provide empirical examples of the ways in which actors deployed ASFNs in the above studies. In particular, we show how ASFNs provide a means by which participants (in both studies) could deflect attention from 'untoward' behaviour (specifically, in relation to feeding the self or feeding infants and other family members), whilst at the same time, maintaining an identity as a 'responsible' adult or parent. Furthermore, we demonstrate two additional aspects of ASFNs as justifications and repudiations for 'untoward' behaviour. Firstly, we argue that they function to legitimise claims to the 'denial of injury' around food practices by making reference to a 'generalised other' in accounts (for example, by claiming that 'everyone knows' it is not possible to cook fresh food from scratch every day). Secondly, we show that by drawing on vague and inexplicit accounts (referred to as systematic vagueness), actors also defended 'untoward' food practices against criticism from others. We conclude by speculating that ASFNs not only offer insights into how contemporary public health messages may be undermined but can also be viewed as a manifestation of resistance to these discourses.

### **'You don't want to open a can of worms': A Discourse Analytic Study of GPs' Reflections on Raising the Topic Of Weight**

*Blackburn, M.*  
(University of Edinburgh)

Amidst an 'epidemic of obesity', GPs are under increasing pressure to advise obese patients to lose weight, yet many are reluctant to raise the topic of weight during consultations. To explain this, previous research has shown that GPs question the legitimacy of obesity as a medical problem, fear disrupting relationships with patients and feel ill-equipped to treat obesity. While, in recent years there has been an explosion of medical, media and political discourse surrounding obesity, little research has attempted to explore how this socio-cultural context contributes towards GPs' understandings of obesity and subsequent barriers to raising the topic with patients.

During one-to-one interviews, twenty GPs were asked to reflect upon video vignettes portraying doctor-patient interactions in which doctors either acknowledged or ignored their patient's body weight. Discourse analysis was used to explore the meanings GPs ascribed to these scenarios, and to identify the cultural beliefs and practices which bring about these meanings. I discuss the medical, moral and ethical discourses identified within participant's accounts, outlining subject positions and the implications for social practice.

I conclude by arguing that disparate discourses surrounding obesity create tension and ambivalence for GPs. Medical discourses surrounding obesity reinforce a reductionist understanding of obesity, placing an undue burden on health professionals. Findings emphasise the need for more sociological research focused on the structures and conditions that produce and sustain obesity stigma within medical consultations.

### **Who are the Harmful Drinkers and How Can we Engage Them? Exploring the Role of Segmentation Analysis to Inform Alcohol Harm Reduction Work**

*Larsen, J. A., Russell, A.*  
(Drinkaware)

Drinking alcohol causes significant harm in the UK. In 2014, more than 8000 people died from alcohol, and alcohol was a contributing factor in more than one million hospital admissions. To support effective work to reduce these figures it is important to understand which individuals are more likely to be drinking in harmful ways.

Segmentation analysis offers a method to identify individuals who have common needs, interests, and priorities. The approach is informed by Bourdieu's ground-breaking theories on social stratification based on aesthetic taste as related to social class (Distinction, 1979), and it has been adopted by marketers and public health professionals, designing and implementing strategies to target groups of individuals.

This presentation outlines work to create a segmentation analysis, based on a UK representative survey of 2,294 adults considering drinkers according to their attitudes and values (openness to moderation, reasons for drinking, mental wellbeing) and their behaviours (risk level of drinking, consequences and harms experienced from drinking). Five clusters were identified: 'comfortable social drinkers', 'controlled home drinkers', 'risky social and coping drinkers', 'self-contained moderate drinkers' and 'risky career drinkers'.

The presentation outlines the methodology used and discusses the value of segmentation analysis to inform alcohol harm reduction work. In particular, the limitations of basing the analysis on survey data is considered in the light of the 'alcohol harm paradox' which shows that people from more deprived social groups are more likely to suffer alcohol health harms, although their reported drinking levels are similar to other groups.

### **'Everyone wants to do what they see on TV' The Role of Media in Alcohol Consumption Amongst Young People in Eastern Nigeria**

*Dumbili, E., Henderson, L.*  
(Brunel University London)

Nigeria has high levels of alcohol consumption, and there is concern that young men and women are drinking harmfully. There is a dearth of studies of young people and alcohol in Nigeria with only a few predominantly

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quantitative surveys. These do not explore the social meanings attached to drinking practices nor do they shed light on potential gender differences. This qualitative study explores the perspectives of 31 undergraduate students (age 19-23 years). It identifies that media consumption shapes drinking behaviour in ways which are highly patterned and gendered. Participants with high consumption of Hollywood films associate heavy alcohol consumption with high social status and associate alcohol with aspirational ideas of economic independence and gender equality. Participants reported that excessive drinking practices such as drinking games were linked to specific popular films. By contrast, local (Nollywood) films depicting the negative impact of alcohol paradoxically appear to support alcohol consumption as an appropriate response to young people experiencing anxiety or depression. Nigeria currently has little regulation of alcohol advertising which is embedded in everyday life. It is important that any attempts to develop wider public health campaigns and policies take this saturated media landscape into account, and public health strategies are linked to media literacy programmes.

## Embodiment and Emotion

STEELHOUSE 3, CAMS

Friday 09 September 2016 at 11:20 - 12:25

### Engaging with Infants: Making of Subjectivity in Everyday Infant Eating, Sleeping, and Body Movement Practices

*Karasaki, M., Veltkamp, G., Bröer, C.*  
(University of Amsterdam)

'Children's perspective' has become a buzzword in childhood research and policy. This interest in engaging with voices of children stems from a conceptualisation of children as competent social actors, who have the right to be heard. While this development has been a welcome shift away from the dominant psychological and biomedical paradigms in childhood studies, it also poses a number of methodological, conceptual, and ethical challenges, especially in research with infants, whose limited language compromises researchers' capacity to hear their 'perspectives'. Another problem with the 'children's perspective' approach is with its treatment of perspectives as entities residing within the individual, which can be accessed and represented through a symmetric participant-researcher relationship. Subsequently, it assumes and privileges a particular kind of knowing subjects: self-reflective, coherent, and verbally-articulate. In this paper, we explore an alternative strategy. Using examples from an exploratory ethnographic study about infant eating, sleeping and body movement, we discuss an approach that allows for conceptualisation of the infant subject capable of a mode of knowing other than that involving cognitive knowledge. Drawing upon the work of Pols (2005), we conceptualise an infant's subjectivity as co-produced in an unfolding event, by the infant, parents/carers and researcher, all of whom are negotiating needs, wishes and desires through embodied forms of communication that may not include a language. This form of engagement involves researchers learning from, and with, parents and infants about how to be sensitive to one another.

### Disclosure and Distress: Bearing Witness and Managing Emotional Disclosures in Health Research

*Clarke, J., Roe, B., Timmons, S.*  
(University of Nottingham)

This presentation explores the role of emotional reflexivity in conducting difficult or distressing health research. There is growing acknowledgement about the importance of emotions in difficult or distressing research (c.f. Hubbard et al., 2001; Bloor et al., 2007; Bahn and Weatherill, 2012; Mukherji et al., 2014). Health researchers often 'bear witness' to participants' distress and face the difficult task of managing their emotions and others' expectations throughout the research process (Jackson et al., 2013), especially where health researchers feel powerless to act or assist others in times of need. Yet researchers often have to present an 'objective' image of the research process and much of the emotional labour and emotional reflexivity, which contextualises and impacts the research interpretations, are stripped from the analysis and eventual write-up.

In this presentation we discuss some of the challenges involved in conducting health research, particularly when the research is difficult or distressing, such as in psychiatric units and major trauma centres. We focus on three aspects of distress and research, which are the interactional dynamics between researchers and their participants, physical and emotional risks and the emotional labour that researchers perform when studying sensitive health related topics. Theoretically, we draw on medical sociology and sociology of health and illness through building upon the work of Hochschild (1979), Ellis and Bochner (2000), and Hubbard et al. (2001). Methodologically, we consider how researchers can most effectively use their emotional responses (Burkitt, 2012) throughout all stages of the research to clearly inform theoretical interpretations.

# Experiences of Health and Illness

## G63, MAIN BUILDING

Friday 09 September 2016 at 09:00 - 11:15

### **Understanding Barriers and Facilitators to Healthy Pregnancies Among Women Living in Poverty Using Timeline Assisted Life History Interviews and Visual Methods**

*Grant, A., Morgan, M., Gallagher, D., Mannay, D.*  
(Cardiff University)

Three-quarters of pregnant women smoke, drink alcohol or are obese and are at increased risk for low birth weight, birth defects and Sudden Infant Death Syndrome (Reilly, 2013). Interventions aiming to improve health in pregnancy often have low uptake and high dropout rates (Gamble et al., 2015; Johnson et al., 2013) or do not produce behaviour change, (Robling et al., 2016). This may be as a result of poor initial understandings of health behaviours, and limited theoretical underpinnings in interventions (Craig et al., 2008).

We aimed to develop an in-depth understanding of multiple health behaviours in pregnancy among women from deprived areas by using participatory approaches. We recruited 10 pregnant women living in deprived areas and claiming benefits or tax credits before they were 20 weeks pregnant. Participants received a stationary pack by post prior to undertaking a timeline facilitated life history interview (Mannay and Creaghan, 2016). Around 6 weeks later, participants chose a visual method to engage with in a second interview from a list including: photography, collage, creative writing, drawing, artefact facilitated interviewing and sandboxing.

We will describe the nuanced understandings of health behaviours in pregnancy, moving away from the issue of simple choice, which is often used in public health interventions, through detailed reference to participants in the study. The methodological challenges inherent in using these methods will also be explored, including participant concerns to create the 'right' answer, the need to provide a range of participatory approaches, and sharing visual data.

### **'I just don't think it's that natural' Exploring Young Mothers Decisions not to Breastfeed**

*Jamie, K., Bows, H., O'Neill, R., Hackshaw-McGeag, L.*  
(Durham University)

The UK's Healthy Child Programme recommends exclusive breastfeeding for six months. Despite health professionals encouraging breastfeeding through the pervasive 'breast is best' rhetoric, rates of breastfeeding in the UK fall far below government targets with 17% of babies exclusively breastfed at three months and just 1-2% exclusively breastfed at six months (Department of Health, 2010). Within this, young mothers are i) less likely to breastfeed than older mothers, ii) more likely to stop 'early' when they do breastfeed, and iii) less likely to breastfeed exclusively.

Drawing on group interviews with 27 young mothers (under-21) from across the UK, this paper highlights the beliefs and experiences which influence their breastfeeding choices and behaviours. In this paper, we particularly focus on young women's decisions not to breastfeed.

We do so by drawing attention to three key narratives in the data. Firstly, many women decided not to breastfeed because they perceived it as unnatural or abnormal. Secondly, the sexualisation of women's breasts meant that other women did not feel comfortable using their breasts to feed their children. Thirdly, for some women not breastfeeding was seen as a way in which to achieve equality in a relationship where responsibility for feeding children could more easily be shared.

We conclude by suggesting that policy initiatives which assume young mothers' choice not to breastfeed is based on a lack of information or a lack of support risk glossing over the complexities and politics of women's breastfeeding decisions.

### **The Fragmented Narratives of Young People Living with Acne**

*McNiven, A.*  
(University of Oxford)

Drawing on an ongoing Healthtalk project looking at young people's experiences of skin conditions, this paper will consider narratives about having acne. Participants recounted a range of ways in which acne has social and emotional impacts on their lives, resonating with previous scholarship on visual differences. However, the narratives of young people with acne also entailed the negotiation of potentially conflicting concerns, including between trivialisation and stigmatisation. These tensions will be explored in the interview data to consider how the young people: (1) negotiated a range of connotations read from their bodies (including that of dirtiness and laziness), (2) positioned their acne as a concern/problem (or not) and (3) made comparisons to others' skins/health. The outcomes, as this paper will demonstrate, are fragmented and ambiguous narratives about living with acne.

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### **The Endometriosis Label: Problematizing the Sick Role as Legitimatised Through Diagnosis**

*Griffith, V.*  
(Durham University)

Endometriosis, a chronic disease which affects approximately 1.5 million women in the UK, is defined as the ectopic placement of endometrial-related tissue, and is characterized by extremely painful menstrual periods, chronic pelvic pain, infertility and pain during sexual intercourse.

This paper is based on an ethnographic study, conducted in the United Kingdom, which shed light on how health professionals and patients negotiate endometriosis. Interviews and questionnaires were undertaken with 35 women suffering from endometriosis and 20 gynaecologists. In addition, participant observation was carried out in a gynaecology clinic and at endometriosis support group meetings. The data collected were coded thematically.

Previous literature on diagnosis and endometriosis projects a view that a diagnosis is the golden chalice, a positive goal where women will attain the 'sick role'. This will allow them to escape the contested aspects of their condition and to gain a legitimacy where their symptoms will be taken seriously.

Results of the present study show that receiving a diagnosis of endometriosis has both positive and negative dimensions and does not ensure symptom improvement. When receiving the label endometriosis, women spoke of a push-pull in that the positive attributes of a diagnosis also carry negative aspects. Women reported being abandoned by the medical community and experiencing sadness and fear. They emphasized that they also faced the added responsibility of feeling better after receiving the endometriosis diagnosis.

## **Health Policy** **WHITEHALL 1, CAMS**

**Friday 09 September 2016 at 09:00 - 12:25**

### **Discourses of Care and Countervailing Powers in the National Health Service Continuing Healthcare Arena: A Grounded Theory Situational Analysis**

*Georgiadis, A., Corrigan, O., Speed, E.*  
(Healthwatch Essex)

In the United Kingdom, complex discharge planning around NHS continuing healthcare has received increased attention due to the human and financial costs it incurs to both the patient and the welfare system respectively, and the potential savings that a more efficient discharge planning process might garner. In this paper we delve into the data that we collected in June 2015 including interviews with staff involved in complex discharges and ethnographic fieldnotes recorded by a researcher who observed the daily clinical activities of the discharge team. Drawing on Light's countervailing powers framework, we explore how the wider discourses of care and caring influence the interactions of the actors and agencies involved in the NHS continuing healthcare decision-making processes. The findings confirm an example of the downward momentum of professional power, which Light supported in his thesis, across the medical professions. Both the discharge team and the ward staff found themselves entrenched within a complex network of power relations that undermined their ability to act as dominant actors in the 'continuing healthcare' arena and deliver patient-centred and evidence-based care with regards to patients with highly complex needs. Their clinical decision-making, which appeared to be influenced by the discourses of evidence-based-medicine and patient-centredness, was relegated by the managerial decision-making of the panel responsible for allocating funding for 'continuing healthcare'. Policy makers need to find innovative ways to integrate the disparate discourses and develop models of care that take into account the different, and, at times, conflicting, practices that each discourse of care espouses.

### **Conditional Politics of Health: Potential Pitfalls in the New NHS Dental Contract Pilots and the Conditionality of Care**

*Laverty, L., Harris, R.*  
(University of Liverpool)

It is over five years since the current NHS dental contract based on Units of Dental Activity (UDAs) was recognised as failing to incentivise prevention and prioritise quality of care. In developing new contracts, a new prototype has begun testing with the aim of rolling out to all dental practices expected by 2018/19. This new prototype system involves rating each patient's oral disease risk and need for care in a traffic-light form (Red, Amber, Green or RAG). However, we argue here that this system has taken on some worrying features since the start of the reform process, and has been inadvertently re-appropriated as a classificatory system leading to unequal access to care. Based on reviewing the new dental contract alongside ethnographic work in practices we propose that the development of different pathways to care based on the RAG systems constitute a conditional health policy. Here, access to care is conditional

on behaviour, often withdrawing care from those most in need. Our aim is not to criticise the NHS dental reforms (they are a well-intentioned attempt to address the deficiencies of the UDA system), but rather to raise concerns about the potential consequences of some of its elements in widening inequalities in access to care. In doing so we make a wider point relevant to the NHS outside dentistry - about the pitfalls in accommodating care for the poorest in society within a system which has efficiency as its main focus, and an ever-increasing emphasis on patients' choice and personal responsibility.

### **Area-Based Health Policy and Adverse Intervention Effects: Bio-Spheres of Risk-Aversion and the Importance of Equity**

*Williams, O.*  
(University of Bath)

Although research has demonstrated that health interventions commonly have adverse effects these outcomes rarely receive adequate academic attention. This paper addresses adverse effects associated with area-based health policy with novel theoretical contributions made for the purpose of improving future policy design and practice. Transformations of the physical and social environment in ways designed to facilitate risk-averting behaviours are theorised here as 'bio-spheres of risk-aversion' and assessed for their potential to address health inequalities. Findings and analysis are derived from a 16-month ethnography in an English neighbourhood which, due to high levels of local deprivation, was the target of a decade-long area-based intervention. Examples from this data are used to illustrate and explain adverse effects resulting from this intervention. Specifically, findings reveal how a local leisure centre built in part to address the structural disadvantages experienced by local residents eventually reproduced the inequality paradox and thus exacerbated existing inequalities. Analysis demonstrates how ultimately this is an outcome of a process that has been conceptualised as the 'waning influence of the past'. Further empirical findings are presented to illustrate how this process eventually progressed to produce a marginalising 'residual effect'. Such findings show that not only are area-based health initiatives liable to increase relative inequality but that they can also further marginalise residents of deprived areas. Practical suggestions are offered for how the design of future interventions can be reinforced against reproducing these adverse effects by conceptualising places as bio-spheres of risk-aversion and committing long-term to achieving equitable outcomes.

### **Activating the Patient: Exploring the Relationship Between Health Policy and eHealth**

*Lynch, A., Pope, C., Vass, V.*  
(University of Southampton)

Demographic changes, notably the aging population and increasing incidence of chronic disease are putting ever more pressures on global health services and systems. Health policy and care institutions have responded by encouraging people to become more proactive in managing their health and disease to lessen burdens on formal health care services. Increasingly referred to as 'patient activation' or patient engagement this practice of activation rests on a series of behaviour changes, in which patients become more knowledgeable and take control over their bodies, disease and treatments. With the growth of eHealth technologies and Web communication platforms, and the popularity of mobile apps and personal health tracking devices, there has been a push for patients to incorporate these digital tools into their self-management. It seems that the Web has opened up new possibilities for creating such activated patients. While there has been some sociological interest in how patients self manage illness, and in the broader concept of the digitised self, there has been less attention to the policy literature and debates surrounding patient activation and these technologies. This paper explores the relationship between eHealth technologies and UK government policy looking at the ways in which discourses of neoliberalism, individualisation and power are reflected in the rhetoric of 'responsibilisation' and self-management. We review the policy discourse and frameworks and show how these merge with eHealth technologies to make the concept of self-management more tangible, and realisable, and ever more attractive to policy makers and health care providers.

### **The Disciplining of Self-Help? Doing Self-Help, the Norwegian Way**

*Hedlund, M., Bodil, J., Landstad, J., Tritter, J.*  
(NORD University)

Self-help is championed as a way of helping people to help themselves; an approach that is seen as particularly relevant for people with long-term conditions. Self-help groups are typically framed in terms of therapeutic communities where the agenda is defined by the members creating a space where open and equal interaction. Such approaches are endowed with the capacity to empower people to change their lives and manage their situation and illness more effectively. Since 2006 Norway has promoted self-help groups as a way of empowering service users to manage their conditions and their lives and potentially lessening the need for clinical interventions and health service utilization. The Norwegian National Nodal Point for Self Help (NPSH) provides training for those who initiate self-help groups and a range of resources as well as engaging with central, regional and local government to embed self-help

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groups in to public health and welfare planning. Drawing on individual testimonies from members of Norwegian self-help groups, self-help group 'starters' and documentation from the NPSH and central government we argue that this tension between a model of self-help premised on lay-leadership and self-determination is at odds with the centrally defined regulation that is apparent in the Norwegian context. This process, we suggest is an example of the disciplining of lay expertise and knowledge that challenges the accepted model of self-help. We used a qualitative explorative design and analysis arguments, utterances in documents, websites and personal told stories available on websites and public documents.

### **Risk and Responsibility in UK Public Health Policy**

*Hutchison, J., Holdsworth, J.*  
(University of Hull)

Recent UK public health policy documents clearly draw on neoliberal discourse to present a series of 'choices' to members of the public around their own health care. This language of personal choice necessarily incorporates ideas of both risk and responsibility which, in turn imply that individuals can be subject to blame for the choices they make. In this paper we explore the consequences of discourses which reflect an increasingly individualised health care system for people living with cardiovascular disease (CVD). CVD accounts for the largest number of deaths in women and the second largest number of male deaths in the UK annually. Improvements in survival rates of CVD mean that that almost 2.3 million people in the UK are living with coronary heart disease. Adopting a 'policy-as-discourse' approach, we draw on both recent policy documents which outline national cardiovascular treatment and prevention strategies and on early findings from the narratives of adults living with cardiovascular disease to better understand the impact these discourses have on people's experiences of illness.

## **Health Service Delivery**

### **STAFFORD 2, CAMS**

**Friday 09 September 2016 at 09:35 - 11:50**

### **All Valuations are Equal, but Some are More Equal Than Others: A Case Study of the Implementation of the IRIS Primary Care Domestic Violence Training and Support Programme**

*Dowrick, A.*  
(Queen Mary, University of London)

Health service researchers are grappling with the difficulties of scaling-up and implementing complex interventions (Cohn, et al., 2013; Craig et al., 2008) to tackle 'wicked' problems (Rittel & Webber, 1973; Law, 2015).

The Identification and Referral to Improve Safety (IRIS) (Feder et al., 2011) intervention is a new programme of work being delivered in primary care in the UK to improve the response of general practice to adult patients who have experienced abuse.

This paper explores the processes of valuation (attributing worth) and evaluation (assessing worth) (Kelberg et al., 2013) that actors involved in the delivery of the IRIS programme undertake, drawing on in-depth interviews, ethnographic observation and document analysis from two case studies of IRIS implementation.

The collection and analysis of data is informed by Normalisation Process Theory (NPT) (May & Finch, 2009), which enables study of the individual, social and material processes of enacting new health care practices.

Findings from this research will problematize the conception of evaluation as an objective assessment of implementation success. I argue that both valuation and evaluation are subjective acts. Evaluation, as a performance of value, is situated in moral and political discourses (Thevenot, 2002).

This research will point researchers towards approaches of generating and implementing interventions that align more closely with the changing landscape of how value is attributed to new practices of health care delivery.

### **'Its like being in a space station': Hospital Visiting and Liminality**

*Underwood, J.*  
(University of Huddersfield)

This paper arises from a PhD research project which asks, 'What are the experiences of adult visitors to acute, NHS medical and surgical wards in England?' The research, with its focus on hospital visitors, differs from the more commonly researched areas of hospital-orientated inquiry, which often involve nurse and/or patients' experiences of more specialist services (eg intensive care, paediatrics or maternity).

Drawing on empirical research involving semi-structured interviews, I argue that hospital visiting is a time of liminality. This paper demonstrates how the use of liminality as an analytic lens permitted identification of explicit and implicit features of the participants' experiences. As everyday roles, identities, routines and social customs of the everyday

were exchanged for the unfamiliar rules and norms of hospital wards, features identified in the participants' accounts include: loss of status and a voice; structural invisibility; being seen as a threat, polluting or dangerous; uncertainty; structural invisibility; communitas; and demands for total obedience (Turner 1974). The analysis suggests that hospital visitors are only successful in meeting the challenges they encounter in the presence of strong supporting ward structures and a well-developed communitas. The research, therefore, adds to medical sociological knowledge and the evidence base for hospital policy-making and professional education and training.

### References

Turner, V. (1974) *The ritual process*. Harmondsworth, UK and Ringwood Australia: Penguin Books Ltd.

### **Barriers and Enablers to Acute Medical Care in Scottish Hospitals**

*Rae, R., Morrison, Z.*  
(University of Aberdeen)

The provision of healthcare services provides significant and unique challenges in an organizational context. The current economic environment puts ever more pressure to operate efficiently in the context of unpredictable demand conditions whilst providing effective solutions to individual's healthcare problems. This article presents the findings from a thematic analysis of qualitative data generated from 191 participant interviews to investigate healthcare professionals experiences of working in the acute medical service across Scottish Hospitals to advance our understanding of the current challenges relating to service delivery and recruitment and retention of healthcare professionals. Valuable tacit knowledge of workforce experiences and opinions have been captured and evaluated to better understand the social and contextual factors relating to the development of acute medical care as a complex intervention and as a medical specialty, as articulated by those working to deliver and develop local services. Three cross cutting themes have emerged from the data to inform understandings of current challenges faced by staff working to deliver acute care, including: the nature and significance of leadership behavior; definitional issues about service provision and identity; and current and potential systems and processes. Findings suggest a blurring of service identity has over time led to a void in role models within the service and impacted on the ability of the service to attract, retain and recruit new talent. We consider ways in which findings may inform recommendations as to potential improvements to the delivery of care and the provision of a sustainable acute medical service in Scotland.

### **Accomplishing Person-Centred Care for Patients with Dementia on Acute Hospital Wards: An Evaluation of the Person, Interactions & Environment (PIE) Programme**

*Godfrey, M., Shannan, R., Skingley, A.*  
(University of Leeds)

**Background:** Improving hospital care for people with dementia is a policy priority. While, person-centred care is conceived of as synonymous with quality care, what this means in practice in a hospital context is unclear and consistent delivery of quality care to patients with dementia has proved challenging.

The study describes how person-centred care for patients with dementia is understood and accomplished in hospital wards and evaluates the process and feasibility of PIE (Person, Interactions and Environment) a qualitative observational tool and change management programme directed at improving care for hospitalised people with dementia .

**Methodology:** A longitudinal mixed-method comparative case study design was used in 10 wards across 5 NHS Trusts to provide in-depth understanding of ward practices and process of PIE implementation. Methods included participant observation of routine care, interviews with staff and patient case studies.

**Results:** We identified several distinct patterns in how care was accomplished in respect of routine tasks and responsiveness to distress; and how these were informed by the care culture, organisational routines and the ward spatial environment. There was variable engagement with PIE implementation. We distinguished between 'non-implementers', 'delayed-implementers' and 'timely-implementers'. Contextual factors affecting implementation included a high degree of structural uncertainty and organisational instability; staffing pressures; active Trust support for practice change aligned with a synergistic dementia strategy ('timely implementer'). There is evidence that PIE implementation resulted in improved care delivery.

# Lifecourse

## STAFFORD 1, CAMS

Friday 09 September 2016 at 10:45 - 12:25

### **Resisting Medicalisation of 'Prolonged' Pregnancy: Women's Experiences**

*Roberts, J., Walsh, D.*  
(University of Nottingham)

Being 'overdue' is a relatively common experience for pregnant women. Over 20% of births in England take place at 41 weeks gestation or more. NICE guidance recommends that induction of labour is offered to women between 41 and 42 weeks gestation, the alternative being expectant management. Induction is associated with reduced risk of perinatal death but the risks remain small and the induction process also carries risks. This paper explores the accounts of women who delayed or declined induction of labour for post-dates pregnancy. Drawing on interviews and an online focus group, we found that concerns about a 'looming' deadline begin before 40 weeks. Women who resisted the medicalisation of 'prolonged' pregnancy, and declined interventions came under sometimes intense pressure and scrutiny. Questions and advice from friends, family and even strangers, reached levels that were unbearable and women isolated themselves by switching off phones and mobile devices. They often found themselves in conflict with midwives and obstetricians and women found it difficult to access the information they wanted to help them make informed choices. The findings are discussed in relation to the literature about the medicalisation of birth, and structural constraints on women's choices in pregnancy.

### **'Compelled to Try' Egg Freezing and Reproductive Citizenship**

*Baldwin, K.*  
(De Montfort University)

As increasing numbers of women and couples delay parenthood, the problem of age-related infertility has emerged alongside the 'ageing population' as a significant modern social problem. As such, the decline in women's fertility, which was once framed as a natural process, is becoming reconceptualised as a medical 'problem' in need of a solution or techno-medical fix through technologies such as egg freezing and ovarian reserve testing.

Drawing on interviews with 31 users of egg freezing this paper will explore how, through the promotion and use of technologies such as egg freezing and ovarian reserve testing, reproductive health becomes a moral responsibility for the neoliberal citizen. This paper will also note how the specific dimensions of these technologies, particularly their transformative possibilities and the way they have the potential to incite action on behalf of the potential user, reflect an intensified process of medicalisation which Clark et al (2010) have referred to as biomedicalisation.

This paper will argue that through these new technological assemblages but also through self-governance, individuals are encouraged to engage in self-monitoring and surveillance when facing the 'threat' of reproductive ageing. It will examine how women's use of social egg freezing can be seen as reflective of 'responsible' reproductive citizenship (Lupton, 2015) which under a biomedical governmentality calls for individuals to 'know thyself' and act accordingly. Finally, this paper will discuss how such messages of responsibility for oneself and one's future lead some women to feel 'compelled to try' egg freezing technologies (Sandelowski, 1991).

### **Poor Sexuality Education and Unsafe Clandestine Abortion Techniques of Young Unmarried Women in South-Eastern Nigeria**

*Amakor, G.*  
(Aston University)

The importance of giving young people sex education is not only to help them evade sexually transmitted infections, but also for them to avoid unplanned pregnancy. Sex education is seen as a vital tool for informing young unmarried women about pregnancy prevention, access and use of contraceptives as well as safe abortion practice. Abortion practice, although largely illegal in Nigeria, is still performed by some unmarried young women in unsafe clandestine conditions due to poor sex education, fear of stigmatization and other factors.

In Nigeria, the cultural silence within families, churches and other agents of socialization on issues of sex, have left young women uninformed about how to live a healthy sexual life and avoid unintended pregnancy. Not armed with the right information regarding sex, young women tend to explore blindly, which in many cases leads to unplanned pregnancy, unsafe clandestine abortion practices and other reproductive health problems.

This presentation will use narratives of young unmarried mothers, as well as individual members of the community and churches to highlight the poor level of sexuality education received by young unmarried women in south eastern Nigeria. It will also look at different clandestine abortion techniques used by unmarried young women and their reproductive health risks. It will argue that the main reason for unsafe clandestine abortion practices is more as a result of poor sex education rather than the illegal status of abortion in Nigeria.

# Methods

## WHITEHALL 3, CAMS

Friday 09 September 2016 at 10:45 - 12:25

### Nodes of Analytic Fixation as Research Scope in Qualitative Research

*Tjora, A.*  
(Norwegian University of Science and Technology)

Using case studies or criteria-based theoretical samples are well established within qualitative research, but is potentially challenging for the purpose of generalisation, especially when 'convenience sampling' is applied (Payne & Williams, 2005). To strengthen potential for theorizing and concept development in qualitative research I elaborate in this paper on the idea of 'Nodes of Analytic Fixation' (NAF's). Examples of such NAF's include events, places/spaces, situations, networks, and stunts. In this paper 'networks' will be explored as an example of NAF, in which health-related communication communities (Delanty 2003) are developed to deal with prolonged health and life style issues, on a basis of (often voluntary) social support. The paper will demonstrate how NAF's are used to concentrate research by combining empirically based (inductive/abductive) curiosity with the research phenomenon, using theoretical sampling (Glaser, 1978; Glaser & Strauss, 1967) to aim for conceptual generalisation (Tjora, 2012) and theory development.

### Reaching Female Entertainment Workers: Challenges and Strategies

*Cheung, O., Wong, M. L., Bt Lim, R., Kt Tham, D.*  
(Saw Swee Hock School of Public Health)

This paper addresses the challenges and strategies of accessing foreign entertainment workers in Singapore. The aim of this study is to understand sexual behaviours of the target group that may put them at risk of acquiring HIV/STI. To gain access to the study population, the author engaged in outreach to Vietnamese and Thai entertainment workers. 420 women were recruited during a 13-month period. This paper examines the challenges of recruiting those who engaged in illegal activities (i.e. selling sex in a foreign country) and the development of culturally sensitive recruitment strategies of accessing this hard to reach population. It also explores the role of gatekeepers in recruiting participants. Lastly, it critically examines the use of survey questionnaires as a method of data collection in this context.

### The Benefits and Methodological Challenges of Conducting User-Led Research: A Qualitative Interview Study of the Experience of Working Age People with Symptomatic Osteoarthritis of the Knee

*Lempp, H., Gillett, K.*  
(King's College London)

There is an increased recognition of the value of user-led research. This paper will describe some of the challenges encountered during a user-led qualitative interview study.

Osteoarthritis of the knee is the most common cause of disability in the UK with pain, stiffness, joint deformity and mobility problems with a substantial impact on the quality of life of patients. Although commonly associated with the elderly, 25% of people aged 45 years and over have osteoarthritis of the knee but limited research exists focusing specifically on the experiences of working age people. Existing studies tend to present the perspectives of health care professionals with a focus on issues such as adherence to and compliance with exercise regimes. This research suggests a practitioner-led, top down approach to research rather than an empowering model for people with osteoarthritis.

This project therefore aimed to explore the experiences and perceptions of working age people with a radiographic diagnosis of symptomatic knee osteoarthritis in relation to (i) treatment decision making, and (ii) self-management. Semi structured interviews were conducted in 2015 with 15 working aged people. The fact that the researcher who conducted the study has osteoarthritis of the knee had potential benefits however a concern was the potential for the user-researcher's experience to take precedence over study participants' narratives. This paper will consider both the benefits and some of the methodological challenges of conducting user-led research and will discuss the approaches taken to mitigate them in this study.

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### Open WHITEHALL 2, CAMS

**Friday 09 September 2016 at 09:35 - 10:40**

#### **'Making Sense' of Reproductive Options: A Qualitative Examination of Reproductive Decision Making in Maternally Inherited Mitochondrial Disease (MD)**

*Maddison, J., Stewart, J., Turnbull, D., Rapley, T.*  
(Newcastle University)

This paper draws on a developing collection of semi-structured interviews (15) with women with maternally inherited mitochondrial disease (MD), offering retrospective and current/prospective accounts of reproductive decision-making. Maternally Inherited Mitochondrial Disease is a group of disorders that are heterogeneous and are caused by defects in the mitochondrial DNA (mtDNA). They are a clinically and genetically diverse group of disorders that are progressive and disabling. There are many complexities in mitochondrial biology that make determining and advising on maternally inherited MD particularly problematic compared to other genetic diseases. These bring with them very specific challenges of uncertainty surrounding inheritance risk. With newly emerging reproductive techniques patients have even more reproductive options than ever before to consider. These include pioneering and recently legislated Mitochondrial Donation, Pre-Genetic Diagnosis (PGD), Surrogacy, Ovum Donation, Genetic Counselling, Pre-natal testing, Natural Conception, Adoption and Voluntary Childlessness.

This presentation focuses on the key finding of how these women make sense of their diagnosis and how this data has enabled us to create an enhanced model of reproductive decision making (Downing, 2005) individual to this unique genetic defect. This work has led to insight into how women are framing their individualised inheritance risk and the factors contributing to decision making, decisions that have been shown to be both fixed and changeable over time. Exploring how these women navigate this complex and emotive issue has provided important data that will assist with implementation of a patient pathway for the first time in the NHS.

#### **A Multi-Perspective Approach Towards the Role of Mass Media within the Medicalisation Process**

*Van den Bogaert, S., Declercq, J., Stroobant, J., Jitomirskaya, V., Jacobs, G., Bracke, P.*  
(Ghent University)

Mass media increasingly inform lay people about health and illness, and shape how people think about themselves and their health. As a consequence, different scholars have argued that people experience their lives as being mediated. Although medicalisation has been studied extensively, and recent studies have acknowledged a greater diversity within medicalisation, little attention has been paid to the role of the mass media within the medicalisation process. Furthermore, notwithstanding their insights into the construction of health news, most studies focus on the content of news messages. However, health news can be studied from different angles. This study wants to expand the analysis beyond the news content towards an analysis of not only what media do, but also how they do it, what stakeholders think media do, and how the lay public perceives this news content.

Drawing on data from a large qualitative and quantitative research project, this study analyses the role of mass media within the medicalisation process. More specifically, by integrating different methodological approaches, we try to define medicalisation within the context of the production, distribution and reception of health news. Our results indicate that by only analysing the news content, the extent to which mass media medicalise is overestimated. Consequently, this multi-perspective approach offers a more nuanced approach towards media and medicalisation.

### **Patient - Professional Interaction** WHITEHALL 3, CAMS

**Friday 09 September 2016 at 09:00 - 10:05**

#### **'I'm her mum I should be the one that holds her' Negotiating Disempowerment; How Parents Find a Role when their Newborn Baby Needs Surgery**

*Hinton, L., Locock, L., Knight, M.*  
(Oxford University)

Background: Understanding of rare congenital anomalies in babies that lead them to require surgery is poor. The birth prevalence of conditions such as gastroschisis and exomphalos is increasing worldwide and advances in neonatal care are improving outcomes. But there remain gaps in our knowledge. Their surgical management is an under-researched area, as is the lived experience of their parents. What is it like to have an infant that requires such intense

complex treatment during his or her early weeks and months? What are the long-term impacts on parents and the wider family?

Methods: As part of a British Association of Pediatric Surgeons-Congenital Anomaly Surveillance System (BAPS-CASS) study, in-depth narrative interviews were conducted with 44 parents who had a baby who needed surgery during the first year of their life for conditions diagnosed antenatally (e.g. exomphalos, gastroschisis, congenital diaphragmatic hernia) and postnatally (e.g. Hirschsprungs Disease). Interviews were video and audio recorded and analysed using a modified grounded theory approach.

Findings: The participants' infants were frequently very unwell and required intense, complex, multidisciplinary care from medical teams for several weeks or months. Parents often found it challenging to finding a role as a 'mother' or 'father' to their newborn. Any parenting they were able to do took place under a public gaze. Parents were faced with extended periods of uncertainty, complexity, isolation and disempowerment.

Discussion: This paper will explore how parents cope and find a role, and how health care teams can support and work with parents during these challenging experiences.

### **Control and Surrender in Human Services Interaction: The Relational Contexts of Living with Motor Neurone Disease**

*Foley, G.*

*(Trinity College Dublin)*

Motor neurone disease (MND) is a terminal condition where 70% of the population dies within 3 years of symptom onset. MND therefore poses a particularly acute challenge for improving services provision for service users who face mounting losses. Services provision in MND is palliative where the timing and sequencing of interventions (i.e. care pathway) occur in parallel to disease progression.

This study used the grounded theory (GT) method to understand how MND service users from their perspective, engage with health and social care services (1). 34 people were theoretically sampled from the Irish MND population-based register and qualitative interviews were conducted with each participant. Data was analysed using GT coding procedures.

The study revealed that MND service users exert control in their interactions with service providers in response to unremitting loss in their lives, including loss of control. Exerting control in services includes the possibility to relinquish control to service providers on one's own terms. Having a say over the timing of services is of central importance to service users as they resign themselves to end-of-life care. Age, life stage, family and parenthood exert a central influence on when service users resign themselves to palliative interventions.

Care pathways are disadvantageous to palliative care if they are understood and deployed as formulas that expeditiously describe and manage the service experiences of service users. The MND service user experience is mediated by the experiential tension between control and surrender - something that cannot be captured by the linear logic of pathways (2).

## **Pecha Kucha STEELHOUSE 3, CAMS**

**Friday 09 September 2016 at 09:00 - 10:05**

### **Gender Differences In MS Diagnoses: A Social Phenomenon?**

*Eccles, A.*

*(University of Oxford)*

Multiple Sclerosis (MS) had been shown to be more prevalent in women, but biomedical explanations for this are lacking. Patterns of disease trajectories are highly varied between individuals and different MS types have been proposed to categorise these; with men having higher rates of primary progressive MS and women having higher rates of relapsing remitting MS and secondary progressive MS. However, these types are somewhat oversimplified and in reality disease patterns rarely fit comfortably into these descriptions. This presentation poses the question whether we should expand further than biomedical explanations and instead be looking to more social considerations to explain apparent gender differences. Other conditions, such as autism and heart disease, have been shown to be gendered, which potentially leads to earlier or later diagnoses according to gender. This presentation puts forward the idea that, and demonstrates how, the different categories of MS types and gender differences might instead be explained by gender differences in when people are diagnosed, rather than biomedical theories.

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### **Coming off Drugs in Prison: The Withdrawing Body and Prison Time**

*Walmsley, I.*

*(University of the West of England)*

The paper will discuss findings from a small scale qualitative study of drug dependent prisoners' experiences of coming off heroin in prison. Research studies on prison drug treatment and recovery approaches, such as medically assisted detoxification and daily maintenance on substitute drugs such as methadone, have primarily focused on risk or evaluating effectiveness or assessing outcomes. Prison researchers have pointed out that such treatment interventions and evaluations are underpinned by a particular conception of prisoners as passive recipients of prison healthcare, rather than viewing them as active participants. This research project developed and extended this criticism by exploring the various ways that drug dependent prisoners were active in their recovery. Ten participants who were recently released from local prisons were recruited with the help of a community drug treatment agency in the South West of England. A preliminary analysis of key themes identified in the interview transcripts revealed the importance of multiple temporalities to the experience of coming off drugs in prison and the practice of self-care. The discussion will locate these themes of temporality and the withdrawing body of the heroin user using existing criminological and sociological literature on time, drug use and time and prison culture.

## **STS and Medicine**

**BYNG KENDRICK - G11, MAIN BUILDING**

**Friday 09 September 2016 at 09:00 - 11:50**

### **Saving 8 Million Lives and 1 Trillion Dollars? Updating Healthy Eating Advice to Include Sustainability Criteria**

*Fletcher, I.*

*(University of Edinburgh)*

Recently published healthy eating guidelines in several countries - including the Nordic countries and France - have included sustainability criteria by, for example, advising individuals to eat less meat or consume local and seasonal produce. Incorporating evidence about the environmental impacts of eating into these guidelines is a difficult task. Research into the effects of diet on population health, and into the environmental impacts of food production form two large bodies of research. Attempts to combine these separate bodies of knowledge into straightforward recommendations for the general public involve complex judgements about how to reconcile sometimes contradictory and incomplete evidence. Developing advice about ideal levels of meat and fish consumption seems to be particularly controversial.

Debates about these new technologies of population health, therefore, provide an excellent opportunity to investigate the development of a novel form of 'policy science' (Jasanoff, 1990). In my presentation, I will first outline the general characteristics of policy science, and then use case studies from twentieth century nutrition advice to discuss the sort of issues that arise in the development of nutritional guidelines by expert advisors and national governments. This presentation is based on the literature review for an interview-based study into the development of sustainable healthy eating guidelines, and, in conclusion, I will outline the more complex debates and issues that I expect my interviewees to discuss when describing the incorporation of sustainability criteria into such advice.

### **Is Sociology Ill-Equipped to Deal with Mental Illness? Accounting for the Multiplicity and Materiality of Eating Disorders**

*Gonzalez Aguado, M.*

*(University of Leicester)*

My presentation discusses the suitability of sociology's conceptual tools and methods to deal with the material aspects and the changing nature of mental illness using the example of eating disorders (ED). Discursive approaches focusing on patients' illness experience have made a very valuable contribution to the understanding of the causes of ED's treatment relapse. I argue however that this type of inquiry has serious difficulties to account for the material and physical underpinnings and the multiple presentations of ED. I argue that, in contrast, an Actor-Network-Theory approach based in the analysis of the medical and non-medical practices at the base of ED can better explain these questions.

ED medical category has experienced major changes in the last three decades. These syndromes shared symptoms and clinical features. Clinical research shows that their diagnostic stability, with the exception of anorexia, is low and patients' crossover frequent. Qualitative health research reports that patients perceive their disorder as something functional to cope with life difficulties and, consequently, as part of their identity. The so-called pro-eating disorders online communities propose alternative non-medical understandings of these pathologies.

Phenomenological analysis reports that practices, instruments and body processes are intertwined in the onset of ED. In order to explain these phenomena, previous sociological approaches suggested that ED are controversial or 'boundary objects' at the intersection of different communities. I rather suggest that these pathologies are multiple: they can be different things in different communities as they are enacted by different set of practices.

### **'Normal Growth'. Unpacking the WHO Child Growth Standards and Malnutrition Measurement**

*Nino, N.*  
(University of Edinburgh)

Since the 1960's, child growth charts have been used in order to assess children's growth, implement nutritional surveillance and compare how different groups of population are growing. In 2006 the World Health Organization (WHO) released their own set of growth charts for international comparison after promoting for thirty years the charts developed by the US National Center for Health Statistics (NCHS). According to the WHO, their charts indicate how children should grow for the best health outcome in contrast to the NCHS charts that indicated how the average child grows. This shift from a descriptive to a prescriptive approach allowed the WHO to claim that their charts described children's normal growth regardless of their geographic and ethnic background.

In 2009, Colombia, along with 140 other countries, adopted the WHO charts. As a consequence of the shift between charts the national malnutrition rate increased. The National Survey of Nutritional Status, for example, reported in 2010 a higher and unexpected percentage of overweight, underweight and stunted children. The shift between charts mobilized new ways of understanding normal growth and therefore under and overnutrition. Using an STS perspective to understand classification, standards and standardization, this paper presents the results of a qualitative study conducted in Colombia. Based on documentary analysis and semi-structured interviews, this paper unpacks the values embedded in the WHO standards regarding children's bodies and their health status and examines how they are mobilized in the production of malnutrition statistics.

### **Crowdfunding and Health Innovation: Dynamics of the Controversy Over the Gobe Glucose/Calorie Self-Monitor**

*Saukko, P.*  
(Loughborough University)

This presentation analyses the dynamics of the emergent practice of crowdfunding health innovations, focusing on the controversy over the GoBe glucose/calorie/wellness self-monitor. Discussions on digital fora and media around the GoBe monitor was analysed for themes since its start in 2014 until 2016. Two broad themes or phases were identified. First, after the Russian developers of GoBe attracted a million dollars on the Indiegogo crowdfunding platform, technology websites attacked them for 'scamming' their backers with a device lacking scientific evidence. The backers were addressed and behaved (by asking for refunds) as consumers, who had purchased a potentially faulty product. Second, after GoBe was launched in 2015, journalists and consumers produced a spate of contradictory reviews, evaluating the wearability, functionality and accuracy of the device by comparing its calorie consumption estimates with those of conventional calorie trackers. Crowdfunding and consumer reviews are often infested with romantic ideas of participatory innovation. Journalists and backers/users had some agency in the GoBe debate, criticising and commenting on the device and its developers; however, they evaluated it in terms of its suitability for a geeky and/or fitness enthusiastic, affluent consumer. The case sends a warning signal about the narrowly consumerist perspective in this novel, allegedly participatory driver of health innovation.

### **Epistemic Infrastructure as Ontological Machinery: Shifting Dynamics of Personhood, Pathology, and Psychiatric Knowledge-Production**

*Pickersgill, M.*  
(University of Edinburgh)

The US National Institute of Mental Health (NIMH) today urges researchers to go beyond existing categorizations listed within the American Psychiatric Association (APA) Diagnostic and Statistical Manual of Mental Disorders (the DSM). Studies instead should seek to contribute to new understandings of psychopathology based largely on biology, and which could enhance therapeutic innovation. The talk will set out what is (perceived to be) distinctive about the work of the NIMH, and discuss key actors' responses to such developments. Through their direct actions and through the contestation they created, the NIMH (and other funders) are directing increased attention to the place and roles of psychiatric symptoms in research – and hence, ultimately, clinical practice and the nature of the selves that are produced through therapeutic interventions. In so doing, the NIMH is seeking to produce a new form of epistemic infrastructure with ontological effects that are beginning to extend beyond the US.

This talk presents new empirical data in an area of broad relevance to medical sociology – i.e. psychiatric diagnosis – in order to cast fresh light on the changing contexts of psychiatric research and practice, and extending conceptual

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debate regarding the connected processes of categorizing pathology and personhood. It draws on 15 interviews with influential scientists and clinicians with important roles in shaping the contexts of US and UK psychiatry (e.g., NIMH officials, senior members of the APA, etc.). The interviews were conducted as part of a Wellcome Trust project on the sociology of psychiatric diagnosis.

# Teaching Medical Sociology

## WHITEHALL 2, CAMS

**Friday 09 September 2016 at 09:00 - 09:30**

### **How Medical Students Think. About Sociology, for Example**

*Dikomitis, L.*  
(Keele University)

This research aims to contribute to our understanding of how social science can be more robustly integrated in medical education. My medical students showed great enthusiasm for sociological learning content, but simultaneously expressed concern and unease with the material and 'the way sociologists think'. Most students had no appreciation of qualitative methodologies and often lacked the vocabulary and theoretical background to engage in a constructive discussion. This two-year study was guided by the following questions: What does one do when critical social science thinking clashes with biomedical thinking? How does one challenge biomedical mind-sets that consider the social and cultural aspects of health 'the fluffy stuff'? How can medical students be encouraged to step outside clinical praxis and consider the bigger picture? Qualitative data were collected in three fieldwork streams in one medical school in north England: participant-observation between 2013-2015 and Critical Incident Questionnaires (n=184), focus groups (n=2) and semi-structured interviews (n=11). After a thematic analysis was applied to the data, with the use of QSR NVivo, following themes emerged: (1) perceptions of 'fluffy' versus 'real' medicine; (2) cultures of the formal and hidden medical curriculum; (3) experiences of teaching, learning and assessment. It might be obvious to social scientists why sociology is recognised by the General Medical Council as a core component of the undergraduate medical curriculum. But, as I will show, it is paramount that those who have a stake in medical education should see its relevance too.



# BSA Medical Sociology Group Annual General Meeting

## Everyone Welcome

We are keen to invite all conference delegates to our Annual General Meeting which will take place on Thursday 8 September in Room 145, First Floor in Conference Aston Building. The meeting will begin at 12:45 and is planned to be finished by 13:45. All delegates are welcome but only BSA Members are eligible to vote on the business of the Medical Sociology Group. The AGM includes our annual report on the activities of the Committee and the awarding of the Phil Strong Memorial Prize, as well as news from the Foundation for the Sociology of Health and Illness and the election for one new member of the editorial board of *Sociology of Health and Illness*. Voting slips can be found in your delegate bag!

This year we will be appointing a new Postgraduate Research Student (PGRS) member and an ordinary member of the committee. If you are a member of the BSA and you are interested in being considered, please ask a member of the Committee at the conference registration desk for a nomination form and make sure you hand in your completed form by 12 noon on Thursday. Elections, if necessary, will take place at the AGM. Please see below for the 2015 AGM minutes.

## Minutes of the General Meeting Thursday 10<sup>th</sup> September 2015, 13:00 - 13:30 Bar Area, Galleria Restaurant, Rodger Kirk Centre

Thirty six members of the BSA Medical Sociological Group attended the meeting. It was chaired by co-convenors Ewen Speed and Fiona Stevenson. Elaine Forester was responsible for minute taking.

### 1. Minutes of the 2014 AGM

The minutes of the Annual General Meeting held on Thursday 10th September 2015 and available to view on pages 157 to 159 in the conference programme, were agreed to be accurate and correct.

**2. Matters Arising** – A huge thank you from Ewen Speed and Fiona Stevenson to all of the MedSoc committee for organising this year's conference.

**3. Convenor's Report** - This report was delivered by Ewen Speed.

There has again been an overwhelming interest in the 2015 MedSoc conference resulting in the largest number of bookings to attend the conference to date. There were 259 delegates in 2010, 305 in 2011, 334 in 2012, 362 in 2013, 366 in 2014 and 369 this year. So the overall summary from the conference is very positive and the outlook for future years is that the conference is going from strength to strength.

The 47th Medical Sociology Conference received 406 abstracts, a 17% increase on 2014, 199 were offered oral presentation slots, with 171 presenting after speaker withdrawals, with 24 posters and 8 symposia/special events including the committee events: Cost of Living Symposium (organised by Ewen Speed and Simon Carter, and kindly hosted by Danny Dorling). As noted above, there continues to be an increase in the number of delegates attending the conference with 369 delegates confirmed to attend this year, 248 for the full conference and 60 as day delegates. The committee maintained the number of funded places again this year with 24 (1 withdrawals) allocated to Postgraduate Students, 4 to unwaged and 4 to sociologists outside academia and 29 funded places allocated to committee members, BSA Staff and invited speakers. There continues to be a healthy international interest in the conference with 24% of delegates attending the 2015 conference coming from overseas. This figure is a 66% increase from 2014.

This year there has been an expansion to the "Mentoring Corner" thanks to an increased number of mentor volunteers. In 2014 we had 3 mentors and this year 12. The feedback from these sessions has been mixed at the moment and the future of this feature will be discussed at the next MedSoc meeting to be held in November. "Pecha Kucha" presentations continue in the programme following their successful trial in 2014. The committee would like to encourage submission for symposia and special events for the 2016 conference. The committee would also like to thank the Wellcome Trust for hosting a Special Event relating to "Sociology Funding Opportunities".

**Early Career Researchers' (ECR) Event** – The fourth annual event has taken place at the 47<sup>th</sup> Annual Conference with 41 attendees. The MedSoc committee would like to thank the organising committee Tim Banks, Sarah Hoare and Matthew Lariviere (co-opted to help while Tim was unavailable) for the work they have undertaken to make this a very successful and well attended event. This event was fully supported by the committee in the form of complementary accommodation and reduced registration fees to all attending. To ensure continuity of the PGRS work, Sarah Hoare will remain on the committee for the 2015-16 year, with a new PGRS member elected during the AGM. There was an additional ECR day held at Cambridge University on the 22 June with 16 delegates attending. The committee supported this event allocating £500 towards the event costs and supporting 5 funded places allocating £50 to each.

**Report from the 'Medicine, Health and Illness Stream' at the BSA Annual Conference April 2015:** 80 papers were submitted to the stream, 57 were offered oral slots, 8 'roundtable discussion' and 5 poster slots, with 10 withdrawals from the conference programme. The committee would like to thank Paul Bissell for delivering the Stream Plenary for 2015. The MedSoc committee would also like to thank Sally Brown and Kate Weiner for all of the work undertaken to ensure the success of the Medicine Health and Illness Stream and for helping to promote Medical Sociology. Ex-MedSoc committee member and Co-Convenor Kate Weiner will be stepping down as the co-stream co-ordinator and will be replaced by ex- MedSoc committee member Julia Hiscock for the 2016 conference. Sally Brown will continue as the co-stream co-ordinator. The abstract submission deadline is 16<sup>th</sup> October 2015 and the stream co-ordinators would like to encourage more symposia/special event proposals. Ian Rees Jones is confirmed as the Medicine Health and Illness stream plenary for 2016.

**Regional / Special Interest Groups** – There continues to be very buoyant actives from most of the Regional Groups, the current active regional groups are East Midlands, North West, North East, South West, Wales, West Midlands, London, Scottish, South Coast and Yorkshire. All regional groups are self-sustaining and can draw on a fund of money which will remain at £400/year per group to help support their activities. The Special Interest Groups of the Sociology of Mental Health and the Applied Qualitative Health Research had previously received £400 of funding, the committee increased this funding in 2014 to £800 and this will continue for the Jan – Dec 2016 financial year. Two new Special Interest Groups have been set up this year "Deconstructing Donation" and Environment and Health". New proposals are welcome from regions who currently do not have a study group. Please contact any of the MedSoc committee for more information.

#### **4. Financial Report** – Ewen Speed presented the financial report

At the end of the financial year (31<sup>st</sup> December 2014) the BSA audited accounts show a credit balance on the MedSoc account of £129,072 compared with £157,411 in 2014. Again the funds were utilised in the year so that reserves decreased in line with planned expenditure. The conference fees increased by £15 for a full conference registration, but continue to be below the 2009 prices of £285.00. Based on current forecast figures for this year's conference at the University of York it is anticipated a planned deficit of just over £23,000 will be generated (based on 359 delegates), compared to a £10,000 deficit from last year's conference. This deficit has been planned to spend down the surplus fund and has been undertaken by the following measures: 1) maintaining reduced fees for BSA members, 2) funding 32 free places for the conference, 3) supporting the early career researcher event 4) funding the Cost of Living blog and MSo, 5) supporting the regional and special interest groups. Based upon the forecasted deficit for the 2015 conference, the closing balance for 2015 should be about £94,149. Demand to attend the conference remains extremely high having reached full capacity seven weeks earlier than the registration closing date. Communication continues to be focused upon with the further development of the Cost of Living Blog.

Reduced spending (in terms of activities) is planned for the 2015-16 year to maintain the reserves at their current planned level of £94,000. All the planned spend down measures are fully reversible and if not financially sustainable can easily be removed from the group's yearly activities.

The financial slides will be available on line for all to view through the Medical Sociology Group part of the BSA website. A view will be taken regarding the 2016 registration fees towards the end of 2015 and registration will open spring 2016 for next year's conference.

#### **5. MedSoc Committee Nominations**

There is 1 Postgraduate Researcher (PGRS) member vacancy  
3 nominations were received

Votes were collected at the AGM and after a count of votes Jenni Remnant from Newcastle University was elected as the PGRS representative.

#### **6. Foundation for the Sociology of Health and Illness – Trustee's Report delivered by Jonathan Gabe**

Post Graduate International Conference Travel Grants received twenty six applications and ten were awarded.

The Mildred Baxter Post-Doctoral Fellowship received eight applications with two awarded.

Symposia and Workshop Support Awards received five applications during the spring of 2015 but none were received for the previous autumn of 2014. All five applications were supported.

Research Grant Development Awards received seven applications during the year with three applications being approved.

As well as supporting the continuing work of the editorial team in Cardiff, the Trustees intend to advertise and fund up to two Mildred Baxter Fellowships, twenty Postgraduate travel awards, eight symposium/workshops and four research grant development groups. All details can be found on the Foundations website.

#### **7. Sociology of Health and Illness – Editor’s Report delivered by Ian Rees Jones**

Original submissions to the journal have increased year on year with 593 submitted during the period 1st September 2014 – 31st August 2015. The acceptance rate for the past year has been just under 26% compared to 21% in the previous year. The Impact Factor for the journal dipped this year to 1.665. This is partly related to the growth in the number of papers published. The queue from acceptance to print publication currently stands at 8 months. The journal has an early view section on the web site. The journal are undertaking a wide range of publicity and marketing activities including virtual abstracts, social media, a redesigned web site and improved links to media outlets. Gareth Thomas and Rebecca Dimond came into post as new book editors in October 2014 and will be in position for at least three years. Ian thanked everyone who has undertaken reviewing for the journal and encouraged new reviewers to register.

#### **8. Sociology of Health and Illness – Board Nominations delivered by Justin Waring**

The constitution of the BSA Medical Sociology Study Group states that two journal board members will be elected at the annual MedSoc AGM . Feedback from last year’s vote at Aston University was that relatively low attendance at the AGM and the established voting convention did not necessarily give all delegates an opportunity to vote. At the spring 2015 board meeting this was discussed and the decision was made to trial a new approach where voting would be available to all delegates over the first two days of the conference. This was subsequently approved by the SHI and MedSoc boards and the new approach is being trialled this year. The process will be reviewed and further ratified at the next SHI board meeting. As this new approach involves a change to the constitution it is being presented to the AGM for deliberation. One comment from those attending the AGM was that this new election process may undermine the importance of the AGM. This comment will be feed back to the board for further discussion. A count of all voting will take place when the poll closes at 17:00 on Thursday 10<sup>th</sup> September and the winners will be announced on the conference notice board as in previous years.

The new writers prize for 2015 has been awarded to D Martin for ‘Architecture and Healthcare: a place for sociology’.

#### **9. Cost of Living Blog – delivered by Sasha Scambler**

The Blog continue to post every week throughout the year except Christmas week. They have received more than 95,000 page views in the first 3 eras of the blog and over 41,000 people accessed the blog in this time. In the past twelve months over 16,000 users accounted for almost 29,000 page views. The number of users has increased but users are accessing less pages, suggesting they are coming to the site specifically to look at a particular post. This ties in with the fact that most visits are on Mondays and Fridays when the new blogs are posted. The current ranking on Google is 5. The site had visitors from across the world with the majority of readers in the UK and North America. This year the site has been optimised for mobile devices and this has resulted in a 5% increase in those accessing the site from mobiles and a further 5% from tablets. There are now 7 members of the editorial collective. The managing co-editors are Simon Carter and Ewen Speed with Editors Hannah Bradby, Charlie Davison, Adan Fletcher, Sasha Scambler and Catherine Will.

#### **10. Phil Strong Memorial Prize**

Ewen Speed reported that this year the Phil Strong Memorial Prize received one applicant: Elizabeth Sutton from the University of Leicester will receive the award the £1,200 to go towards her field work in Patient Safety.

#### **11. Any other business**

The next Annual General Meeting will be held at Aston University, Birmingham during the 48<sup>th</sup> Annual Conference on Thursday 8th September 2016.

The minutes of the 2015 AGM will be printed into the programme of the 2016 conference.





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