

Social Science & Early HTA Reflections from the MATCH project

Julie Barnett

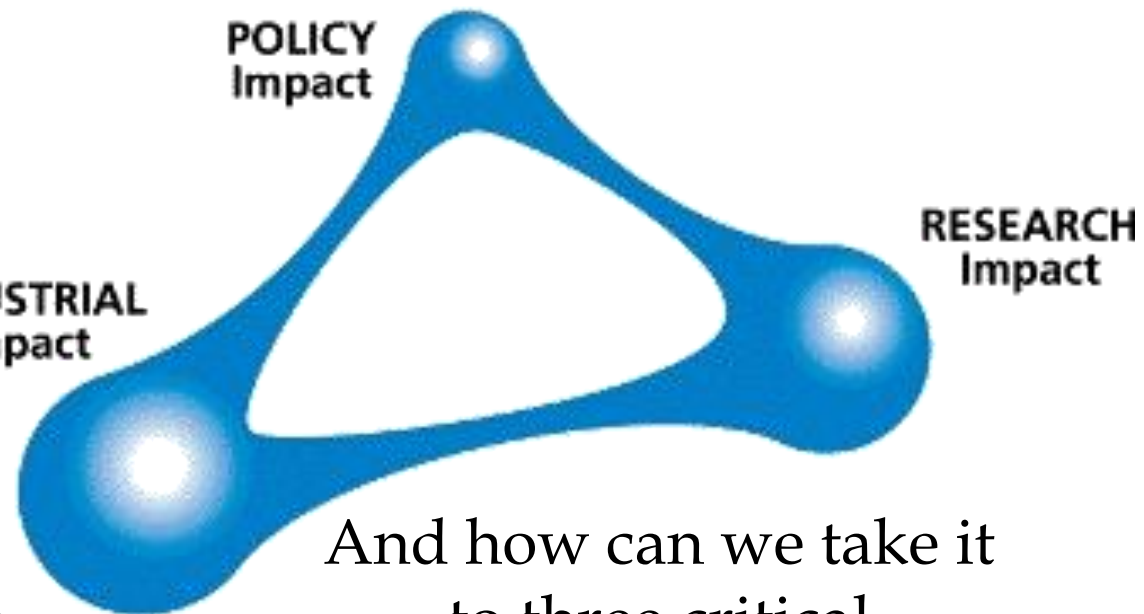
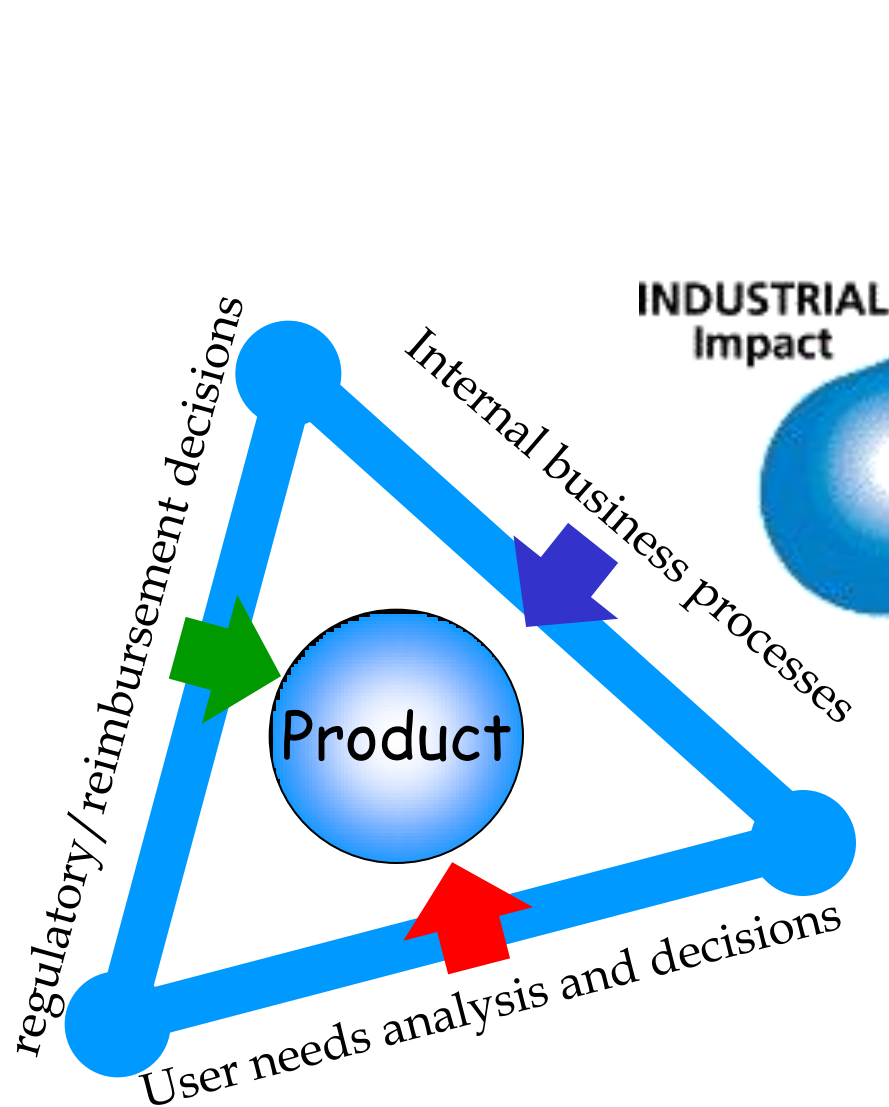
Professor in Healthcare Research

Brunel University



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Is there a common view of value?



And how can we take it
to three critical
communities of
stakeholders?



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Decisions and development



Concept



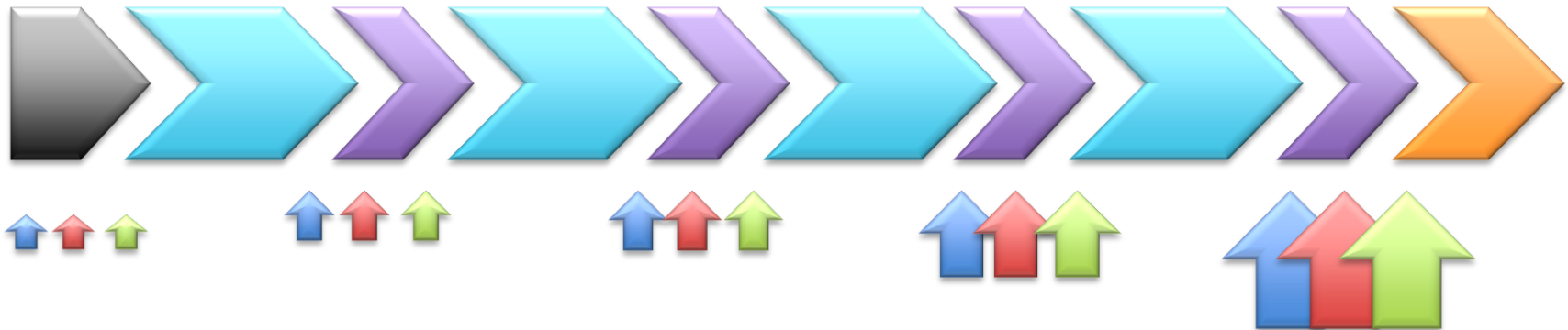
Phases of work



Decision points



Product launch



Internal business knowledge



User involvement



Economic evaluation and regulatory knowledge

BMJ

BMJ 2013;346:f2614 doi: 10.1136/t

Page 1 of 2

**OK to ask about clinical
research – the NIHR's
new patient
empowerment campaign**



ORIALS

Let the patier

Patients can improve he

Tessa Richards *analysis*
Lapsley *patient editor*¹,

The NIHR has launched a new campaign to empower patients and encourage engagement in clinical research – and we are calling on all NIHR-funded researchers to take part.

The it's 'OK to ask about clinical research' campaign launched on International Clinical Trials Day, on 20 May and is aimed at encouraging patients and their carers to ask their doctors about clinical research and whether it is right for them.

*tor in chief*¹, Peter



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Patient and public perspectives

Increasingly patient and public role in co-production of research/technology assessment is normative across range of policy and practice domains

Broad challenges around production of acceptable evidence

Methods

Hierarchy of evidence

Organisational barriers

Resource allocation

Being in favour of public consultation . . . is rather like being against sin; at a rhetorical level, it is hard to find disagreement (Harrison & Mort, 1998)

Limited momentum of participation? Nature of participation remains constrained. Compelling evaluation of participation is scarce.

Motivations for participation

- Normative:
participation is just the right thing to do
- Instrumental:
it is a better way to achieve particular ends
- Substantive:
it leads to better ends

“Dialogue...at the right point in the process, can help scientists and policy makers ensure that scientific and technological developments go with the grain of public opinion and therefore enjoy wider public support than they might otherwise have done” .

Push and pull?

Evidence about patient/public perspectives vs. perspectives of publics/patients

- Focus tends to be on evidence that can be easily incorporated within health economic & clinical assessments
- Less focus on psychosocial and organisational impacts of health technologies
- Important role of champions
- Involvement of patients/publics may not increase public acceptability

Does participation that is 'pushed' from normative motivations – that is not rigorously evaluated – and thus cannot demonstrate its substantive value – run the risk of diluting the potential 'pull'*?

* Pull from HTA community/projects/medical device companies

People may not want to participate...

Carol Sarler



Please,
just leave
us out of
the loop

Your starter for 10: how many speed bumps would you need, on a 374-yard stretch of road, to reduce the velocity of the morning traffic by an average of 8.4mph? And for your bonus question: how many used speed bumps would you need to reduce the velocity of the morning traffic by an average of 8.4mph? No?

What you are asking for is an extraordinary thing. It is something that all know the answer to: the people who are in charge of democracy, 'community' policy, regardless of that any civil service is remotely equal to the previous 'community' relative wisdom versus the last week's waste of an eight-page questionnaire produced, distributed, and at some great cost to us that its

publisher, the London borough of Haringey, is declining to share with me – complete with natty snaps and pull-out maps, the better for

sufficient commitment, intelligence and ability first to identify critical issues and then to find, and use, the

" The reason we fetch up for our local elections is not so that we may have our neighbourhood ruled by the madness of guesswork but so that we may elect representatives of sufficient commitment, intelligence and ability, first to identify critical issues and then to find, and use, the greater expertise available"

neighbourhood ruled by the madness of guesswork, but so that we may elect representatives of suf-

At worst, it's an abnegation of informed responsibility: it's not our fault it didn't work, Guv. It's what the People wanted.

Real life is messy

“It will always be a part of the policy landscape to have indecisive ministers, policy conflicts, staff turnover and too few resources. Take all that as given and think of what to do about it”

(National School of Government, Workshop materials, June 2007)



Early assessment of medical devices

Push for MDDs to integrate user views

- Regulatory, funding requirements

SME case study limited evidence of pull *from* MDD

- Verbal articulation of findings and implications did not translate to action
- Few contingencies of user work around development decision points
- Unanticipated findings around clinical need posed unwanted challenge

Reasons for limited 'pull'

- Loose coupling of relevant organisational functions
- User involvement peripheral element in mental model of successful development
- Confirmation bias
- Other stakeholders may constrain likely pull – e.g. ethics*time interaction; procurement focus on cost
- Focus on users with influence as well as interest.

Money, A.G., Barnett, J., et al (2011) The Role of the User within the Medical Device Design and Development Process: Medical Device Manufacturers' Perspectives, *BMC Medical Informatics and Decision Making*, 11:15

*Martin J.L. & Barnett, J. (2012) Integrating the results of user research into medical device development, *BMC Medical Informatics and Decision Making*, 12, 74



Responding to the methods challenge: PPI in early HTA

Requirements for early patient and public involvement

- Allow the articulation of values and frames
- Encourage question and challenge to information and underlying assumptions
- Enable speedy, efficient and systematic participation
- Introduce unfamiliar issues in an engaging way
- Identify areas of concern, uncertainty, scepticism and misunderstanding
- Explore differences between groups



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Introducing VIZZATA: on-line participation

- Discover what questions people have
- Track information seeking behaviour
- Explore differences between groups
- Provide bite size chunks of content – text, video, images
- Elicit the questions and comments that participants have
- Measures attentiveness to information
- Enables on-going engagement with participants

HOW THE METHOD WORKS



Methods for capturing and analysing existing information

EDITORIAL

Patient-centred healthcare, social media and the internet: the perfect storm?

Ronen Rozenblum,¹ David W Bates^{1,2}

¹Division of General Internal Medicine, Brigham and Women's Hospital and Harvard Medical School, Boston, Massachusetts, USA

²Department of Health Policy and Management, Harvard School of Public Health, Boston, Massachusetts, USA

Patients are central to healthcare delivery, yet all too often their perspectives and input have not been considered by providers.^{1 2} This is beginning to change rapidly and is having a major impact across a range of dimensions. Patients are becoming more engaged in their care and

are increasingly using the internet to share and rate their experiences of health care. They are also using the internet to connect with others having similar illnesses, to share experiences, and beginning to manage their illnesses by leveraging these technologies. While it is





Social media: potential to reveal user perspectives?

Social media is a group of internet-based applications and platforms that allows users to create and exchange content

- Interactive, dynamic, collaborative
- User-generated content.
- Multi-directional communication flows

Social media platforms

BLOGS....

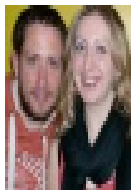
CUSTOMER REVIEWS

SOCIAL NETWORKING SITES — MICROBLOGGING SITES —

Most Recent Customer Reviews

★★★★★ I am alive!

my
2004, age



Tweets



iMedicalApps.com @iMedicalApps
Almostadoctor app brings free medical encyclopaedia to iPhone
[#meded](#) [#medapps](#) [ow.ly/aoTty](#)

1m



Mike Clark @clarkmike
NY Times looks at safety issues with implanted medical devices
[nyti.ms/Jhyxzu](#)

2m



Medical News @MedicalNews
FDA says focused on tracking drugs after approval [bit.ly/l2rYjr](#)

4m

recording of
cancer.

Like · Comment · Follow Post · Share · Yesterday at 7:47am

know CPR and you are not in panic mode, you
MIGHT have problems. The BIGGEST downside
to this unit is TWO PADS. [Read more](#)
Published on September 3, 2009 by Howard

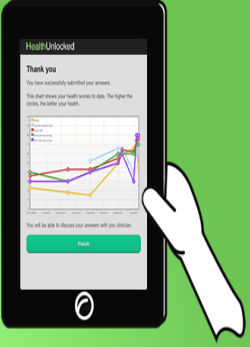


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Health Tracking

Patient-reported outcomes made easy

Learn more ▶



Latest communities

- [Couch to 5K \(NHS Choices\)](#) **NEW**
- [Behcet's disease \(ABDA\)](#) **NEW**
- [Cavernoma \(Cavernoma Alliance UK\)](#) **NEW**
- [Cancer \(Tenovus\)](#) **NEW**
- [Sjögren's Syndrome \(TASSA\)](#) **NEW**
- [Charcot-Marie-Tooth disease \(CMT UK\)](#) **NEW**
- [Restless Leg Syndrome \(RLS-UK\)](#) **NEW**



Communities

Support and answers for patients, families and carers

Learn more

GP Communities



Share your health profile

Answer simple questions to create a shared health profile to see how you're doing over time.



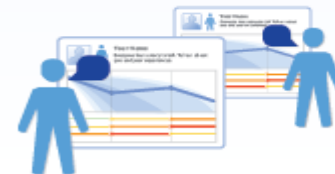
Find patients like you

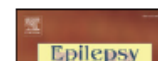
Search by gender, age, treatments, symptoms, and time since diagnosis to easily connect with patients like you.



Learn from others

Learn from real-world treatment and symptom reports, forum discussions, health profiles, one-on-one conversations and more.





nature
bi

Journal of Medical Internet Research

The leading peer-reviewed journal for health and healthcare in the Internet age

Health Care Professionals' Beliefs About Using Wiki-Based Reminders to Promote Best

Perceived
an online

Paul Wicks^{a,*}
Jouko Isojärvi

^a PatientsLikeMe Inc., C

^b UCB Pharma SA, Brus

^c UCB Inc, Raleigh, NC,

Patient-reported Outcomes as a Source of Evidence in Off-Label Prescribing: Analysis of Data From PatientsLikeMe

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¹VU Amsterdam, KankerNL, Amsterdam, Netherlands

²PatientsLikeMe Inc., Cambridge, MA, United States

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Diabetes_Sanofi @Diabetes_Sanofi

19 Apr

MT @askmanny: Pls RT: #Diabetapedia Likes + Tweets May Help Create a @D_Advocates' Scholarship Fund @diabeteshf! bit.ly/HUztdB #DSMA



Cherise/LADA @SweeterCherise

19 Apr

#DSMA Live with Hasan Shah (@jdrfadvocacy) Tonight , 9 PM EST ow.ly/1KOcjB #dsmaLive



Kerri / Diabetes @sixuntilme

19 Apr

The drummer from the band that sings "Closing Time" has type 1 diabetes. So there's that. #dsma



Scott Strumello @sstrumello

19 Apr

Q7. The one thing I want my endo to know abt DM is how exhausting and unrewarding self-care really is b/c chronic disease stinks. #dsma



Kelly / Diabetes @KellyRawlings

19 Apr

Q6 Really, my clinic needs WAY more CDEs and to make that part of every visit and to ask how is mental health. #dsma



Tony : Diabetes @blogdiabetes

19 Apr

Q4: I'm just grateful that I have insurance that pays for a lot. #DSMA

share

Share to friends

share

about

Diabetes
diabetes
people
conver
meanin
created
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makers
and se
experie

Guidance for Industry Responding to Unsolicited Requests for Off-Label Information About Prescription Drugs and Medical Devices

U.S. Department of Health and Human Services
Food and Drug Administration
Center for Drug Evaluation and Research (CDER)
Center for Biologics Evaluation Research (CBER)
Center for Veterinary Medicine (CVM)
Center for Devices and Radiological Health (CDRH)

December 2011
Procedural

- Provides guidance about a particular set of circumstances: Where your company gets an unsolicited and public request via social media about one of your company's products

You can respond, but follow these rules:

1. **Public** response should NOT include off-label information (i.e., don't provide full response publicly)
2. Answer should include note that request pertains to off-label usage, that people can contact medical staff, and contact info
3. Response must only be given directly and privately to the requestor and not posted publicly
4. Public response should include disclosure of involvement with a specific company
5. Responses must not be promotional in nature
6. Include standard response information (package insert, etc)
7. Maintain proper records of response





Mobilising social media around health

Professionals

- recruitment for clinical trials;
- professional development and training for clinicians;
- emergency and disaster communication
- public health messaging
- infectious disease monitoring
- product recalls

Patients

- health social networks and health & illness support groups
- development of interactive, self-management tools
- Formal complaints and patient feedback mechanisms

Why attend to social media?

- Gives you more information?
- Gives you better information?
- Gives you different information?
- Gives more precise information?
- Gives you the same information more easily and economically?



Informing innovation in device development

Supply based strategies capture and analyse what is **published** on the internet

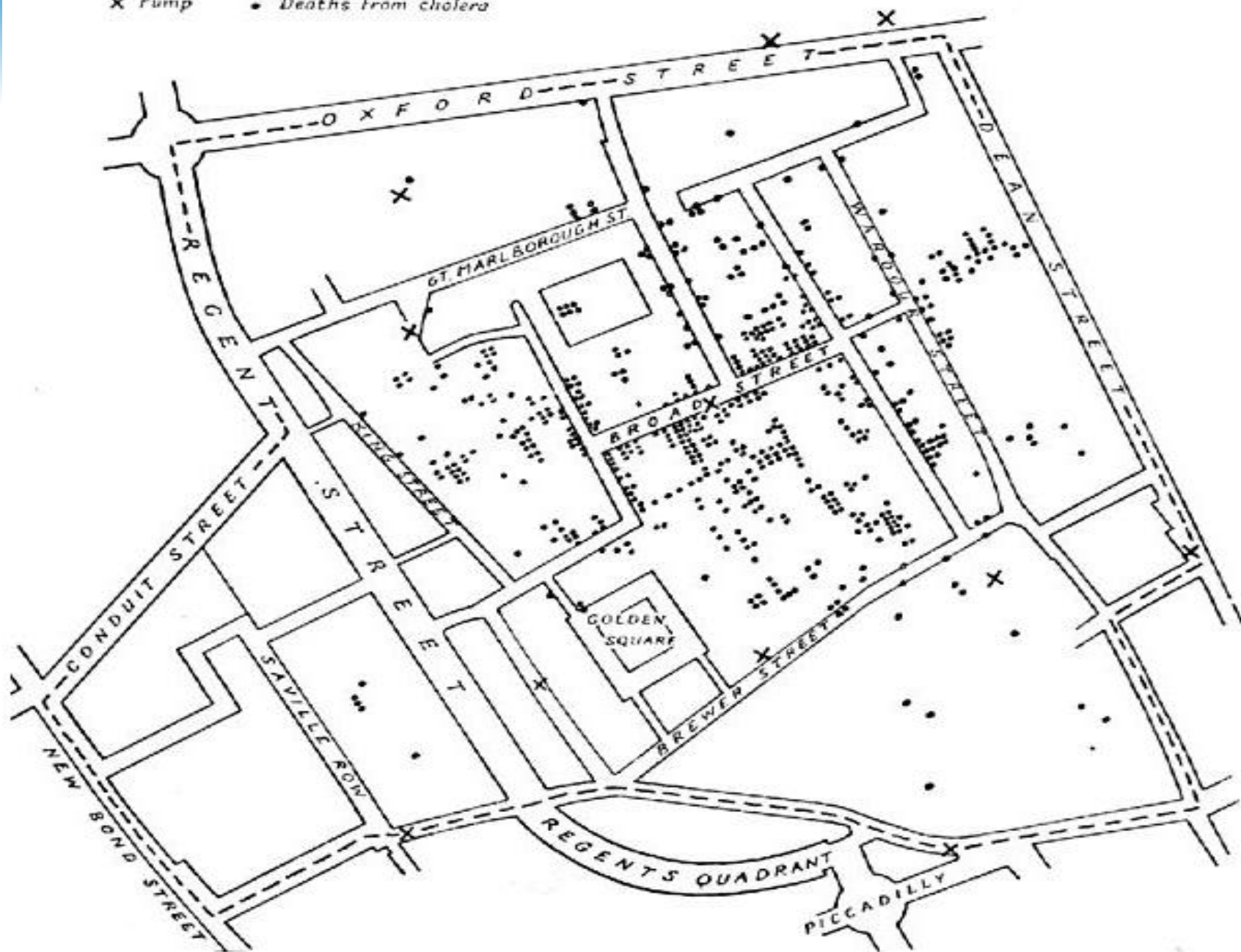
- Can what people are talking about in (e.g.) blogs/micro blogs be used to provide useful information

Demand based strategies capture and analyse what people are **searching** for on the internet?

- Can the search terms people use provide useful information?

50 0 50 100 150 200
Yards

X Pump • Deaths from cholera





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Epidemiology to infodemiology

- Dr John Snow, tracked the 1854 Broad Street Cholera outbreak in London's SoHo district.
- Recorded the locations of the 600 cases of Cholera and spoke with Soho residents to learn more about how the disease spread
- Concluded based on the locations of the cases and personal encounters that the Broad Street water pump was the main agent responsible for spreading Cholera.
- Similar to the idea of a "mash up": combines a digital map with the real time tweets from Twitter users talking about the Swine flu.



Can Twitter be a useful source of public health information?

Dredze & Paul filtered out 1.5 million tweets from 2 billion public tweets between May 2009 - October 2010 that referred to health matters.

- Mention of a range of health ailments in and how range of medicines were being used
- Could distinguish between types of allergies and see timing of start of allergy season in different US States
- Can't just look for simple words: e.g. "High price of gas is a **headache** for my business" or "Got Justin Bieber **fever**".
- Can't see how long illnesses last
- Limits to what people are willing to share

Using social media data

Tweets can be used for real-time content analysis and knowledge translation research

- 2009 H1N1-related tweets were primarily used to disseminate information from credible sources, but were also a source of opinions and experiences¹
- Forecasted box-office revenues for movies from rates at which tweets are created about particular topics. This outperformed market-based predictors²

¹Chew C, Eysenbach G (2010) Pandemics in the Age of Twitter: Content Analysis of Tweets during the 2009 H1N1 Outbreak. PLoS ONE 5(11): e14118

²Asur, S. and B. Huberman (2010). Predicting the future with social media.



Early MATCH research with social media

- Analysing patient blogs around INR use¹
- Customer perceptions of defibrillators in product reviews²
- Exploring social media landscape using data visualisation software³

¹Shah SG, Robinson I. Patients' perspectives on self-testing of oral anticoagulation therapy: content analysis of patients' internet blogs. BMC Health Serv Res. 2011;11:25. doi: 10.1186/1472-6963-11-25.

²Money, A., J. Barnett, et al. (2011). "Public Claims about Automatic External Defibrillators: An Online Consumer Opinions Study." BMC Public Health 11(1): 332.

³<http://chorusteam.tumblr.com/>



Value?

Potential benefits

- Information in real time/over time
- Unsolicited information
- Accessible and potentially less expensive information
- Potential source of intelligence about public sensibilities - process not easily accessed by traditional methods

Problems

- API rate-limiting: data with 'holes'
- Social media data is not gathered like any other kind of social science data
- Do we know who our sample is (and isn't)? Are they 'participants'? What implications might this have for analysis? Are there ethical issues?

Chorus

A Data Collection and Methodological Toolkit for using
Twitter data

The Chorus Tools

- Chorus-TC (TweetCatcher)
 - Browser-based service
 - Two modes of data collection
 - ‘Semantically-driven’ – finding key words
 - ‘User-driven’ – finding and following people of interest
- Chorus-TV (TweetVis)
 - Desktop application
 - Two modes of analysis
 - ‘Time-line explorer’
 - ‘Cluster explorer’





Time line explorer

Time dependent event based analyses

Data ordered chronologically:
analysis based around temporality

Metrics we can use to explore the data

- Novelty: inter-interval dissimilarity
- Homogeneity: within interval similarity
- Positive and negative sentiment – sophisticated and reflexive database vocabulary



About ecoli

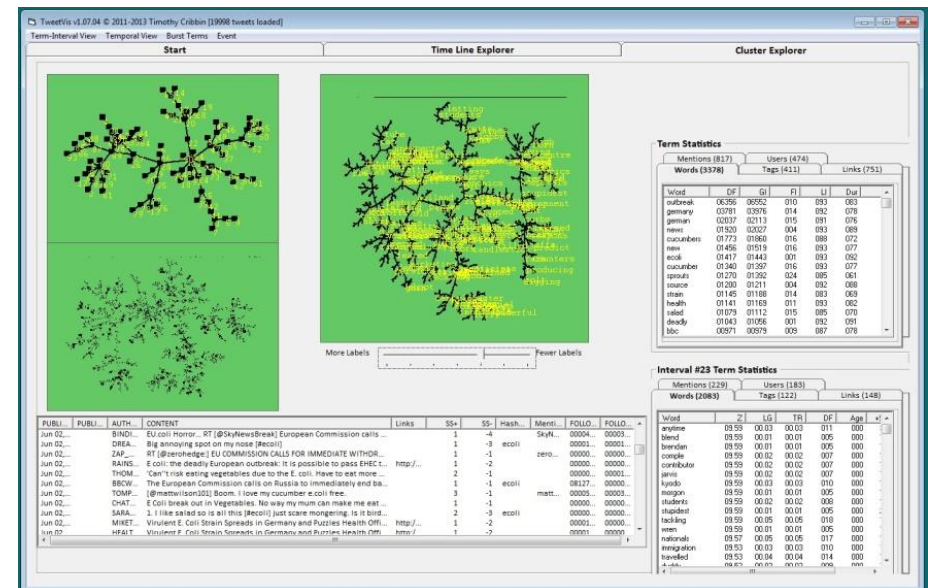
Can see clear patterns of link use (Link ratio) in the early days - gradually changes to expression of opinions/emotions/articulation of coping strategies

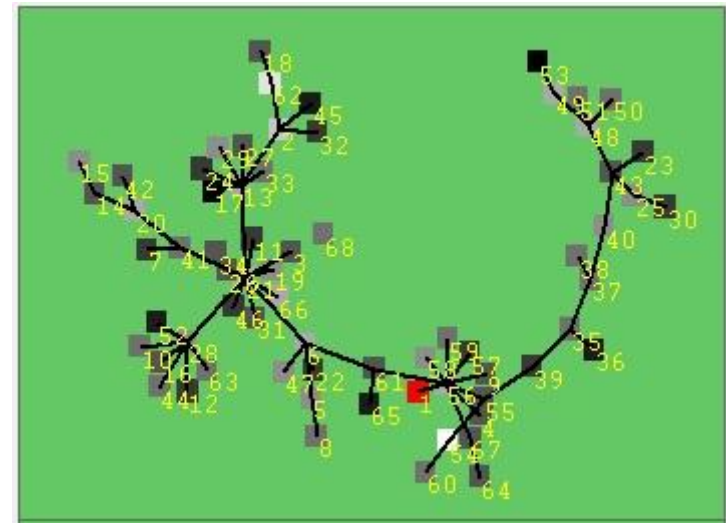
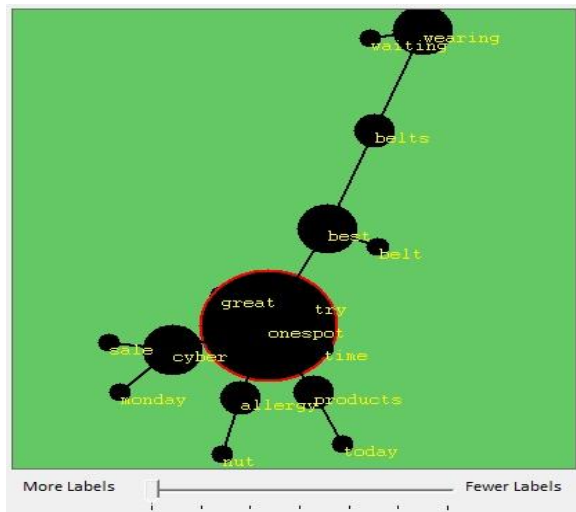
Can see the nature of links – overwhelmingly BBC – little reference to primary sources

Cluster explorer

Non-time-dependent (topic-based) analysis

- No chronological ordering
- What are the topics and themes in your data and how do they relate to each other?
- What are the main 'nodes' of interest on a particular topic?





UserName	Tweet
Onespot_Allergy	Cyber Monday Sale today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen Belt
SGArnold	RT [@Onespot_Allergy:] Cyber Monday Sale today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen Be ...
akaratedad	RT [@Onespot_Allergy:] Cyber Monday Sale today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen Be ...
alergenfreegals	RT [@onespot_allergy] Cyber Monday Sale 2DAY only Onespot Allergy products are 15 off. Great time 2 try our EpiPen Belt
Onespot_Allergy	RT [@alergenfreegals:] RT [@onespot_allergy] Cyber Monday Sale 2DAY only Onespot Allergy products are 15 off. Great time 2 try our EpiPen ...
Onespot_Allergy	[#CyberMonday] [#Sale] today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen Belt
gratefulfoodie	RT [@Onespot_Allergy:] [#CyberMonday] [#Sale] today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen B ...
phaesomething	RT [@Onespot_Allergy:] [#CyberMonday] [#Sale] today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen B ...
AllergicChild	RT [@Onespot_Allergy:] Cyber Monday Sale today only All Onespot Allergy products are 15 off. Its a great time to try our Best EpiPen Be ...



Evaluating CHORUS

Working with 4 medical device developers

What insights can CHORUS provide?

What assumptions to developers bring – about users, about social media

Further development of the software in line to enhance value

Final reflections

- Importance of demonstrating substantive value of patient and public participation
- Rigorous embedded evaluations needed
- Recognise the organisational barriers that militate against a pull on public/patient participation
- Develop methods that are attuned to early deployment in HTA
- Consider the way in which social media can be a resource for informing about clinical need/ (sub) cultural sensitivities

THANK YOU FOR LISTENING



Any questions?

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