Social Science & Early HTA
Reflections from the MATCH project

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Is there a common view of value?

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

Concept

Phases of work

Decision points

Product launch

Internal business knowledge
User involvement
Economic evaluation and regulatory knowledge
OK to ask about clinical research – the NIHR’s new patient empowerment campaign

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.

Tessa Richards analysis, Lapsley patient editor, Peter
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
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.
"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.


*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
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

1. Present bite-sized bits of content
2. MEASURABLE FEEDBACK
   - Elicit questions & comments prompted by content
   - Participants respond
   - Measure interaction with content
   - PLUS: standard online survey
3. Researchers respond to participants' questions
4. MEASURABLE FEEDBACK
   - Participants respond
   - Capture final reflections
5. Option for ongoing interaction

Try the demo more
Methods for capturing and analysing existing information

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

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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 healthcare. 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 –

Microblogs

Tweets

iMedicalApps.com @iMedicalApps
Almost a doctor app brings free medical encyclopaedia to iPhone
#meded medapps ow.ly/acTty

Mike Clark @darkmike
NY Times looks at safety issues with implanted medical devices
nyt.ms/Jhyxz

Medical News @MedicalNews
FDA says focused on tracking drugs after approval bit.ly/l2rYjr

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

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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
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 and Research (CBER)
Center for Veterinary Medicine (CVM)
Center for Devices and Radiological Health (CDRH)

December 2011
Procedural

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

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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/microblogs 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?
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
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 experiences\(^1\)
- Forecasted box-office revenues for movies from rates at which tweets are created about particular topics. This outperformed market-based predictors\(^2\)


Early MATCH research with social media

- Analysing patient blogs around INR use\(^1\)
- Customer perceptions of defibrillators in product reviews\(^2\)
- Exploring social media landscape using data visualisation software\(^3\)


\(^3\) [http://chorusteam.tumblr.com/](http://chorusteam.tumblr.com/)
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 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
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?
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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