

Supplementary information

Title: Public perspectives of using social media data to improve adverse drug reaction reporting: a mixed methods study

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Appendix 1: Online survey

1. Which health conditions do you currently have or take medication for? (Select all that apply)

- Heart disease
- High blood pressure
- Lung disease
- Diabetes
- Stomach
- Kidney disease
- Liver disease
- Anaemia or other blood disorder
- Cancer
- Depression
- Osteoarthritis or degenerative arthritis
- Rheumatoid arthritis
- Back pain
- No health condition or medication taken
- Other medical problem(s)

2. Do you take any regular medication (i.e. a medication you take every day or every week)?

- Statin (e.g. Atorvastatin)
- Antiplatelet (e.g. Aspirin, Clopidogrel)
- Anticoagulant (e.g. Warfarin, Apixaban)
- Blood pressure tablets (e.g. Ramipril, Amlodipine)
- Inhalers or nebulisers (e.g. Salbutamol, Ipratropium)
- Anti-diabetic treatment (e.g. Metformin, Gliclazides, Insulin)
- Indigestion tablets (e.g. Omeprazole, Ranitidine)
- Sleeping tablets (e.g. Zopiclone)
- Anti-depressants (e.g. Citalopram, Sertraline)
- Immunosuppressants (e.g. Methotrexate, Adalimumab)
- Simple pain killers (e.g. Paracetamol, Ibuprofen)
- Weak Opioids (e.g. Codeine, Dihydrocodeine)
- Strong Opioids (e.g. Oramorph, Fentanyl)
- Chemotherapy
- No regular medication
- Other (please specify)

3. Approximately how many years ago did you start taking any regular medication?

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- More than 10 years

4. Have you ever experienced a side effect you believe was caused by your medication?

- Yes
- No

5. Did you report the side effect to any of the following? (Select all that apply)

- Pharmacist
- GP/ Hospital Doctor
- Family/Friend
- The UK regulatory agency (MHRA)
- Directly to the drug company
- Other (please specify)

6. Have you ever had a side effect that led to any of the following? (Select all that apply)

- Stopping the medication
- Visit to GP
- Visit to specialist in hospital
- Admission to hospital
- Long term disability
- None of the above

7. Please rate your level of knowledge about the following (1 being no knowledge and 5 being very knowledgeable)

- Methods of monitoring medication safety
- Laws and regulation surrounding medicines safety
- MHRA (Medicines and Healthcare products Regulatory Authority)
- Yellow Card scheme
- How to complete a yellow card

8. Who do you think should be responsible for reporting drug side effects? (Select all that apply)

- Your doctor or nurse
- Pharmacists
- Drug companies
- Patients taking medications
- Don't know
- Other (please specify)

9. Which of these do you think are important reasons to report and monitor drug reactions? (Select all that apply)

- To find other people with similar reactions
- To learn how common such reactions are, or find out how many other people have had the same problem
- To help prevent similar side-effects happening to other patients
- To help doctors make a diagnosis
- To be recorded within my health record
- Other (please specify)

- 10. Would you be happy for the MHRA to use content posted on HealthUnlocked communities to help monitor side effects? (Only de-personalised information would be used)**
- Yes
 - No
- 11. Would you be happy for researchers to use content posted on HealthUnlocked communities to help monitor side effects? (Only de-personalised information would be used)**
- Yes
 - No
- 12. Which of these would you find easiest to fill in a Yellow Card when reporting a suspected drug side effect?**
- Telephone
 - Online form
 - Mobile app
 - Paper form
- 13. Would you be happy to submit a Yellow Card report from within HealthUnlocked?**
- Yes
 - No
- 14. Which of the following would make it easier for you to complete Yellow Card submissions online? (Select all that apply)**
- Link to the Yellow Card website from HealthUnlocked
 - Suggestion to complete a Yellow Card if your post describes a side effect of medication via a promoted link to the Yellow Card website
 - Suggestion to complete a Yellow Card if your post describes a side effect of medication via a pop up Yellow Card form in HealthUnlocked
 - Suggestion to complete a Yellow Card if your post describes a side effect of medication via a pop up Yellow Card form in HealthUnlocked, with the form partially filled in automatically from details of your post
 - Other (please specify)
- 15. If you could submit a Yellow Card form via HealthUnlocked, what would make you more likely to submit one? (Select all that apply)**
- Keeping your identity anonymous
 - Feedback from your report
 - Confirmation of action taken from your report
 - Further information about the medication
 - Connecting to other HealthUnlocked users that have had similar side effect from medication
 - Advice on how to manage medication side effects
 - No incentive needed
 - Other (please specify)
- 16. How old are you?**
- 16-18
 - 18-24

- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- Over 85 years

17. What gender do you identify as?

- Male
- Female
- Other
- No fixed gender
- None
- Prefer not to say

18. What is the highest level of education you have completed?

- None
- Primary school
- Secondary Education (GCSE/O-Levels)
- Post-Secondary Education (College, A-Levels, NVQ3 or below, or similar)
- Vocational Qualification (Diploma, Certificate, BTEC, NVQ 4 and above, or similar)
- Undergraduate Degree (BA, BSc etc.)
- Post-graduate Degree (MA, MSc etc.)
- Doctorate (PhD)

19. What is your employment status?

- Full-time employment
- Part-time employment
- Working full-time in the home
- Unemployed
- Retired
- Retired early due to ill health

20. What is your ethnicity?

- White
- Irish
- Any other white background
- White & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background

- Caribbean
- African
- Any other black background
- Chinese
- Any other ethnic group
- Prefer not to say

Appendix 2: Focus group topic guide

1. Introduction

Summarise the purpose of the study and focus group. Remind participants that the focus group is being digitally recorded, and that all identifying information will be removed from the focus group transcripts. Allow participants the opportunity to ask questions and check that they are happy to continue.

2. Use of online health forums to discuss medicines

What are the main ways in which you have used online forums to discuss your health?

- What sort of things have you discussed?
- What were your reasons?
- Benefits/drawbacks

Have you discussed your medication use on an online forum before? [*May not require specific prompt if it comes up naturally*]

- What sort of things have you discussed?
- What were your reasons?
- Benefits/drawbacks

What does the term 'side effect' mean to you?

- How would you recognise one?
- Have you heard of the term 'adverse drug reaction'?

3. Use of data from online health forums

Do you think information about medication side effects from online health forums could be useful to others? *If so, how? To whom?*

4. Yellow Card Scheme

Have any of you heard of the Yellow Card Scheme?

- How would you describe it?
- [If anyone has heard of it] Have you used it? *Explore*

Follow up by explaining what it is using the Yellow Card website (*show on laptop – key info copied for ref below*)

The Yellow Card Scheme is vital in helping the MHRA monitor the safety of all healthcare products in the UK to ensure they are acceptably safe for patients and those that use them. Reports can be made for all medicines including vaccines, blood factors and immunoglobulins, herbal medicines and homeopathic remedies, and all medical devices available on the UK market. From the 20th of May

2016, the MHRA is also collecting reports of safety concerns associated with e-cigarette products through the Yellow Card Scheme.

The Scheme collects information on suspected problems or incidents involving

1. Side effects (also known as adverse drug reactions or ADRs)
2. Medical device adverse incidents
3. Defective medicines (those that are not of an acceptable quality)
4. Counterfeit or fake medicines or medical devices
5. Safety concerns for e-cigarettes or their refill containers (e-liquids)

It is important for people to report problems experienced with medicines or medical devices as these are used to identify issues which might not have been previously known about. The MHRA will review the product if necessary, and take action to minimise risk and maximise benefit to the patients. The MHRA is also able to investigate counterfeit or fake medicines or devices and if necessary take action to protect public health.

- If you haven't heard of it, is it something you would consider using?
 - What would encourage you/ put you off?

5. Linking data with MHRA (Medicines & Healthcare products Regulatory Agency)

How would you feel about things that you have posted on online health forums about ADRs being directly linked to the MHRA?

- What would be the best way to do this? Are there other ways this could be done?

Now, we'd like to ask you about some ideas some of our colleagues have thought of for improving reporting. We'll go through each in turn and we'd like you to tell us what you think. [*Remind that these are just ideas and that their honest opinions are important to us*].

How about ...(*describe each option, answer questions and check understanding*):

- A link to the Yellow Card website from the social media site
- A promoted link to the Yellow Card website, suggesting you complete a Yellow Card *if your post describes a side effect of medication*
- A blank Yellow Card form in a pop up, *if your post describes a side effect of medication*
- A Yellow Card form in a pop up, *if your post describes a side effect of medication*, but this time with the form already partially filled in using details of your post e.g. the medication and side effect

6. Closing

Remind the participants of their right to withdraw from the study, and that any identifying information will be removed from focus groups transcripts. Remind participants of contact details and encourage them to ask questions at any stage. Provide payments and expenses.

Appendix 3: Qualitative themes yielded by focus groups: provenance, relevance and indicative strength

	Theme & description	Relevance to:		Provenance i.e. codes (sub-themes) contributing to theme	Indicative strength i.e. separate instances coded (N)*
		Survey question	Results section		
1	Knowledge about ADRs and reporting methods: How participants defined and understood ADRs ('side effects') and knowledge about background reporting mechanisms	4-9	3.2, 3.3	Definition of ADRs	8
				Experience of ADRs	22
				Prior knowledge level of YCS	16
				Use of YCS	9
2	Use of online forums: Benefits and risks of discussing health on online forums, including medication	N/A - outside of scope	3.3. (limited to discussing medication)	Online forum-benefits	17
				Online forum - risks	11
				Discussing medication - benefits	34
				Discussing medication - risks	20
3	Attitudes towards linking with YCS: Discussion of proposals for links between HealthUnlocked and the Yellow Card Scheme	10-15	3.4, 3.5	Benefits and advantages	23
				Risks and disadvantages	66
				Safeguards	2
				Suggestions	47
	Other: Useful quotes, outlier views, other notable content not easily coded elsewhere.	N/A	Throughout, as needed – e.g. to select illustrative quotes	N/A	N/A

*Note that each section of text varied in size (phrase to paragraphs) and could be coded to multiple nodes. Each individual can also have multiple instances coded. As this is focused on verbal content, please bear in mind this does not include non-verbal communication (e.g. nods of agreement).

Appendix 4: Benefits and risks of proposed new methods to improve reporting to the Yellow Card scheme, as provided by focus group participants (* applies specifically to one or more automated methods), with example quotes

Benefits and advantages	Illustrative quote
Using social media to promote the YCS could help to raise awareness of the YCS among a large section of the population	I do [think it's a good idea], yeah, because there's people are already saying they've got side effects, and plainly the two do need to be linked because those people may not know about the yellow card, like we didn't. (P4, Thyroid/lung) I suppose it would create awareness for the younger generation that might not know about it (P3, Lung)
It directly links patients with the MHRA, rather than patients having to rely on health professionals	Nobody asks them to ring them up and say I've had this side effect. And my GPs not going to tell them if I go back to them. (P5, Fibro) It needs to come from us, not the GP, because I told my GP I'm experiencing that. (P13, Thyroid/lung)
It could help to provide timely access to information for patients by signposting links at the time patients are searching for and/or discussing side effects*	If it's a relevant thing then you don't mind the pop-ups. If you're talking about tablets and the side effects and then this advert pop-ups saying please tell us about your side effects, well, I wouldn't mind that. That's why I'm on there in the first place, to try and talk about and find information. (P2, Fibro)
It could be a more efficient, modern way of supporting research*	I think it's modern way of trying to get more research.. it's a more modern way of doing it, if you're already on a site. It's just moving on with the times, I guess. (P3, Lung) Today's technology allows for, like you say, links to be created... if you could do that so that your Facebook forum, closed in brackets, feeds directly into the Yellow Card scheme and other like sites, then you could have all the information collated at one point.(P13, Thyroid/lung)
Partial completion could reduce the effort for patients involved with reporting*	At least it's linked into what you've actually been saying. So then you're not having to put the whole lot of information in. You're just going to put your own personal bit in. (P5, Fibro)
Risks and disadvantages	
The amount of personal information required to complete a report is not necessary and off-putting	I don't think I'd want to put where I live, I don't really think that's relevant (P7, mental health) I think because they're asking for email, phone number, home address, full name, and then they're asking what medication you're taking. I don't think they need to know all that information (P5, Fibro)
The focus on reusing online content could exclude the experiences of people without digital skills or access to internet	My Dad's savvy with a computer, just not, you know, social media. Whereas my granddad, if he had any problems, he would not be able to access this. And I'd say that it's not just really older generations (P7, mental health)
Mistrust of how the data might be used for future medicines safety purposes	I suppose the information could be 'massaged' – for want of a better word – to try and sort of decrease the importance of the impact of the side effects. (P6, Thyroid/lung)

	If you put a complaint in about it, will it be stopped for other people with fibro, is the question? (P12, Fibro/RA)
Automated methods risk further erosion of privacy and civil rights*	It kind of feels a bit like Big Brother. (P11, Fibro/RA)
Mistrust of pop-ups for security reasons, including use of ad blockers*	Because they're just going to see it as a scam. Somebody trying to get your details off you. (P8, Fibro/RA) I suppose some people block pop-ups as well, so it might not come up. (P3, Lung) If I didn't recognise something I'd research what it was and complete it if I wanted to. (P3, Respiratory) I think you'd have to be sure that it wasn't some rogue pop-up, because that's the main thing. And I think people would be wary of it. (P9, Respiratory)
Popups can be annoying or distressing*	I think a lot of people might find it a bit...you know, if they think that some of their conversations were going to be picked out, they might feel their safety's a bit compromised. (P10, Mental health)
Automated methods may take patients' comments out of context, be prone to bias and/or errors*	I think on social media, because you don't have to type it, I think it would be quite difficult because you can just film it and put it on your story for 24 hours and delete it if you want to ... that's going to take a very complex algorithm to realise all the different accents, all the different ways of saying depression or antidepressant...the <i>context</i> (P7, Mental health) You need to check yourself the details have been put in right (P9, Lung)

Appendix 5: Venn diagram displaying agreement patterns to different proposed methods to improve side effect reporting to the Yellow Card scheme, as per survey responses.

Legend: Numbers indicate number of survey respondents who agreed with each of the following methods: link to the Yellow Card website from HealthUnlocked ('link'); suggestion to complete a Yellow Card via a promoted link ('promoted_link'); suggestion to complete a Yellow Card via a popup ('popup'); or suggestion to complete a Yellow Card via a partially completed popup ('popup_part'). Overlapping segments indicate agreement to multiple methods. Note that two smaller overlaps are not shown in order to optimise the layout in a 2D format. Venn diagram produced using the eulerr library in R.

