

Optimising the safety and effectiveness of the Asthma + Lung UK (ALUK) Asthma Online Health Community (OHC): a qualitative interview study with moderators

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1. Background

- 4.3 million adults in the UK have asthma, with a third experiencing suboptimal control, which impacts quality of life and healthcare costs¹.
- OHCs are increasingly used for health advice, and represent an untapped resource to foster asthma self-management.
- However, there are often concerns about the safety and effectiveness of advice given (by other patients) in OHCs and there is lack of current research in this area².

2. Aim

To develop recommendations for the ALUK OHC moderators to follow, that will optimise safety and effectiveness of the OHC.

3. Methods

- Qualitative design: in-depth interviews, audio-recorded on Zoom, with current ALUK Asthma OHC moderators.
- Verbatim transcripts analysed thematically (data driven).
- Next step: Develop and implement written recommendations.*
- Next step: Re-interview moderators to examine impact.*

4. Results

4.1. Participants

- 6 moderators of the asthma OHC (all the current moderators)
- 6/6 female; 5/6 White/White British, 1/6 Mixed (White British/Black African); ages range 33-63 years (mean 44.8y).
- Job roles are presented in Table 1.

Moderator role	Employer	Years of experience	Mode of work	Time spent moderating
Patient ambassador (n=1)	Voluntary role; experienced forum user and asthma patient	1 year	Part time (has other, paid employment)	2-5 hours/week, particularly out of office hours/at weekends
Specialist respiratory nurse (n=4)	ALUK	1-5 years	Part time (3), full time (1)	Work as a team; 1 hour/day, during office hours
Customer support manager (n=1)	HealthUnlocked	1 year	Full time	Manages a number of HealthUnlocked online communities

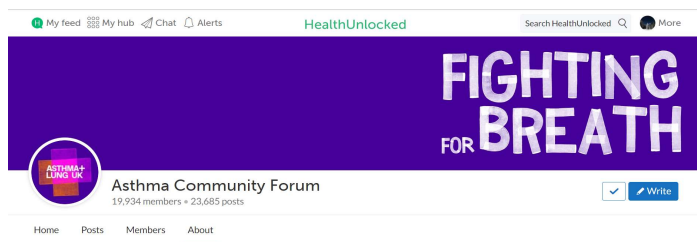
Table 1. OHC moderator roles

5. Conclusions

Our preliminary results highlight areas for improvement of safety and effectiveness of the moderation process. There may be limitations to implementing the moderators' suggested improvements, depending, for example, on functionality of the OHC platform. If found to be effective, the recommendations may be applicable to other OHCs and health social media platforms.

Acknowledgements We sincerely thank the moderators for contributing their time, experience and insights to this study.

References (1) Mukherjee M, et al. The epidemiology, healthcare and societal burden and costs of asthma in the UK and its member nations: analyses of standalone and linked national databases. *BMC Med* 14, 113 (2016). <https://doi.org/10.1186/s12916-016-0657-8>, (2) De Simoni A, et al. Superusers' Engagement in Asthma Online Communities: Asynchronous Web-Based Interview Study. *J Med Internet Res*. 2020;22(6):e18185



4.2. Preliminary findings

Preliminary results are summarised under three themes:

- Challenges in moderating:** 1) heavy reliance on user reports to identify issues; 2) potential for missing problematic posts; 3) lack of time; 4) striking the right balance between keeping users safe and not stifling discussion.
- Effective conversations:** 1) users adding something useful in a reply; 2) users having their questions answered; 3) keeping users safe and offering reassurance; 4) making users feel welcome, especially new users.
- Optimising safety and effectiveness:** 1) include more key words in automatic flagging; 2) send automatic replies in response to certain key words; 3) use systematic method for checking new posts; 4) more activity/user engagement/discussion; 5) encourage more people to join.

"It's about the balance between not letting things run away and get unhelpful or hostile, but letting people have a discussion. That's the thing I find most challenging. Being there but not being too in their face about it."
Moderator #1

...the purpose of a moderator is to keep people safe...for that to be effective it's about communicating clearly about any risks that somebody's put out there, correcting that information or deleting that post.
Moderator #6

I don't know how one could do it better to be honest. Unless you had some automated...key words...it would be things like... 'herbal' would be one I'd put in there definitely...
Moderator #6

I think it's effective if people come in and give them information or things to think about that they haven't considered or they weren't looking for because they didn't realise that they wanted it.
Moderator #1

I think it's people sharing their personal stories that people really like and their experiences.
Moderator #4

If you were going to do it effectively, you'd need to have a lot of time. It could almost be a full-time job really, just going through and reading every single post. I would definitely find it a struggle without my ambassador because she looks at things out of hours.
Moderator #5