



Guidelines for the Cicely Saunders Institute Public Involvement Forum

INTRODUCTION

The Cicely Saunders Institute (CSI) Public Involvement Forum is intended to be a safe and constructive discussion space for researchers, patients, carers and other members of the public to discuss palliative care and rehabilitation in general, palliative care and rehabilitation research, as well as more specific discussions about CSI projects. ALL forum participants' contributions and varied experiences are equally valued and welcome.

Please take a few minutes to read this document in full before posting your first contribution; it is intended to give you a sense of what you can expect as a forum user and what is expected of you.

All participants are responsible for following these guidelines.

SUPPORT ONE ANOTHER AND BUILD A COMMUNITY

- **Respect diversity of people, experience and views.** Individuals' unique experiences and perspectives are what make discussions rich and informative. Although you may disagree with someone's view, please respond in a respectful and constructive manner. We believe forum participants' ethnicity, gender, sexuality and religious beliefs reflect the diversity we find in our society.
- **Be patient** with other participants and read all comments before you respond to an earlier post. This way you can ensure you are not repeating a point someone else has already made.
- **Help others** who may not be as tech-savvy or experienced with forums as you are, for example by responding to questions on the help forum.
- **Participate** because it only works if everyone gets involved!

YOUR COMMUNICATION STYLE

- **Tone.** When having a face-to-face conversation we communicate with the words we say, as well as our tone of voice and facial/body language cues. In an online forum we rely entirely on our words to convey meaning and it is very easy to be misunderstood. It's a good idea to read your post aloud before hitting 'send'. This way you can ensure your sentence structure and grammar are correct, but also that you're happy that your tone and meaning are clear.
- **Consider your writing style.** Think about the language you use and your writing style. Overly formal or scientific language, and the use of terminology or acronyms that are specific to your professional background, might alienate people from the discussion. On the other hand, internet and texting abbreviations (e.g. 'CU L&R!') or slang can detract from the point you are trying to make.
- **Be clear and concise.** This is a much more effective way of getting your point across and more conducive to dialogue than long monologues.
- **Emoticons** 😊 😊 😊 These can be useful in online discussions, but try not to overdo it!
- **NO YELLING! Be mindful of the potential impact of using capital letters** - it can be difficult to read and may give the impression you're shouting.



CONTENT OF YOUR POSTS

- **Personal information.** Although participation in this forum requires registration, it is open to all members of the public and you should be careful about sharing personal or identifiable information. You should not share personal information such as your phone number or email address on the discussion boards. If a researcher posts on the forum looking to arrange additional face-to-face opportunities for involvement, you will be asked to email the researcher directly rather than posting contact details on the virtual forum.
- **Thread.** A 'conversation' or 'topic thread' is a chain of discussion about one particular matter. If you would like to start a discussion about a specific topic or theme, you should be careful to use a meaningful title for your thread so people are clear on the topic.
- **Stay on topic.** Try not to get too distracted from the topic at hand. If another issue comes up that warrants further discussion, consider starting a new conversation thread.
- **Cite your sources.** If your post includes the intellectual property (or 'IP') of others, (i.e. books, newspapers, journal articles or images), make sure the proper attribution is given.
- **No Flaming.** 'Flaming' is a word for hostile and insulting responses or interactions online, often featuring the use of profanities. Criticism must be constructive, well-meaning and well-articulated. Rants or tantrums, particular those targeted at other users will not be tolerated.
- **No advertising.** Do not post messages which advertise commercial products or services.
- **No medical advice.** Discussions on the forum will often be related to health, but this forum must not be used for giving or receiving medical advice.

POST APPROVAL

Some posts may be subject to approval before appearing on the website. Therefore, there may be a slight delay between your post being submitted, and it being viewable to all users.

MODERATION AND COMPLAINTS

A site moderator will respond to complaints or concerns in relation to users' behaviour.

If you are concerned about another user's behaviour, please report it to the site moderator via email: csi.ppi@kcl.ac.uk.

Complaints about a user's behaviour on the forum will be taken seriously. Upon receiving a complaint the site moderator may take one of the following actions, at the discretion of the site moderator and depending on the severity of the offense:

- Issue a warning to the offending party;
- Suspend access to the offending party for a finite period of time; or
- Permanently ban the offending party from participating on the forum.

PLEASE REPORT TECHNICAL ISSUES

Please report any technical issues to support@csipublicinvolvement.co.uk



VOLUNTARY INVOLVEMENT, NOT RESEARCH PARTICIPATION

Participation in this online forum is voluntary and users will not be reimbursed for their time.

Aside from research directly evaluating the virtual forum, this forum will not be used for recruitment of study participants or to collect information (or 'data') that will be directly used in research projects. Rather, it is intended that the content of discussions will help to shape future research questions.

RESEARCHERS FROM OUTSIDE OF THE CICELY SAUNDERS INSTITUTE

Researchers and professionals from other organisations are welcome to bring their expertise to the discussion pages. However, please note that the CSI Public Involvement Forum is currently in pilot form and does not have the resources to support discussion of external (non-CSI) projects. If you are a researcher and you are interested in finding out more about our experience of setting up a virtual forum, please do not hesitate to contact Sophie Pask (Sophie.pask@kcl.ac.uk) or Lisa Brighton (Lisa.brighton@kcl.ac.uk).

CONSULTATION PERIOD

From June 14th 2016 this document will be under consultation with forum users, and may be changed in the next few months.

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