



EPSRC-SFI Joint Centre for Doctoral Training in Engineered Tissues for Discovery, Industry and Medicine ([lifETIME CDT](#))

Research Together: Patients Guiding the Future of Science

Action Summary

All feedback and recommendations expressed during the Research Together event held on 1st February 2023 at the University of Glasgow have been reviewed and discussed by the lifETIME management board. We have incorporated the thoughts and ideas of all attendees and developed the action summary below. Appendix A details the titles of all the topics discussed during the event.

Specific Charities/Conditions

No	Action	Owner
1	Form a group of researchers, clinicians, and others to work with societies where the CDT has strengths (e.g. Multiple Sclerosis Society, Blood Cancer Research UK and Scar Free Foundation) with the hope to become more involved with clinicians and hospitals in connection with these conditions (Topic 1).	PPIE Committee
2	Consider what more we can do as CDT in response to “orphan” (rare) conditions (Topic 13). For example, form a rare disease cluster that is inclusive to all patients with orphan conditions in our future outreach and engagement. An example is developing ideas relating to osteosarcoma and Bone Cancer Research Trust, as well as conditions such as ERB’s palsy (Topic 19).	PPIE Committee
3	If we received future funding, we should develop a strategy to achieve stronger presence for infectious diseases in our research projects (Topic 22).	Interdisciplinary Committee
4	Counteract misinformation about new technologies in diagnostics, vaccines, treatments for infectious diseases. We need to tackle this through PPIE (Topic 22). Make sure we don’t cause panic through principles of responsible research and innovation – all our students are trained in RRI, but perhaps enhance or refresh this training ahead of PPIE events.	PPIE Committee/Skill Training Committee
5	Work with support groups (and potentially industry) to get patients involved earlier in medical device design (Topic 10). Bring clinical, industrial and research information to patient support groups.	PPIE Committee

6	Consider developing use of humanised/computational models to test side effects of alternative drugs for blood cancers and other diseases (Topic 29).	Management Group
7	Students should identify a charity associated with their research, where possible (Topic 4, 6, 14 and 31).	Management Group
8	Consider collaborations with smaller charities collectively to create bigger events and, therefore, more influence (Topic 26).	PPIE Committee

Communication

No	Action	Owner
1	Organise training on engaging and communicating with a lay audience, potentially the training could be run by a journalist (Topic 3). Create opportunities for students to practice lay presentations (Topic 24).	PPIE Committee
2	Consider how to make information e.g., podcasts more engaging for the public (Topic 25 and 27).	PPIE Committee
3	Develop a quarterly student led newsletter to send out to patients. The workload for this would need to be shared and there should be mechanisms for patient feedback (Topic 32).	Student/PPIE Committee
4	Form a “friends of the CDT” patient group from the current group of patients that have already engaged with the CDT (Topic 8). Extend our patient network further to as many demographics as possible via patients, charities, researchers, and industry (Topic 21).	Management Group/PPIE Committee
5	Use Facebook as a social media platform to connect with patients (Topic 23) and include carers, their voice can sometime be the main voice heard (Topic 28).	Management Group
6	All students are required to write a lay summary for their projects, which will be displayed on our website alongside existing descriptions (Topic 8). Lay summaries could be shared with our CDT patient groups for comments/improvements.	PPIE Committee
7	Strongly encourage PhD students to speak with patients during their PhD (Topic 30) to increase visibility of research to help overcome barriers to patient engagement (Topic 11). Students should make use of existing	PPIE Committee/ Management Group

	networks, talking to charities relating to the specific conditions being researched (Topic 5).	
8	Develop guidance (dos and don'ts) for the students to refer to before engaging with patients (Topic 16 and 28).	PPIE Committee
9	Ensure proper communication with patients about ethics of use of samples and cells (more than a consent form) (Topic 15). <i>This is more of learning point.</i>	PPIE Committee

Management

No	Action	Owner
1	Form a PPIE/charity management committee (Topic 5).	Management Group
2	Consider how to combine humanised/computational models with animal models as an interim step towards replacing animal models (Topic 9).	Management Group
3	Where possible, encourage charities to be more transparent about funding decisions; the CDT can influence others by being a model for this (Topic 12).	Management Group
4	Speak to the student researching lab-grown meat to ensure they feel fully supported within the CDT as this PhD project is the only research within this field within the CDT (Topic 17).	Management Group
5	Highlight the impact of reagent costs on charity funding. More work is needed on experimental plans. The trend is unfortunately in the opposite direction with more requirement from publications for experiments to be repeated many times (Topic 12).	Management Group
6	Conduct some PPIE in low resource communities or with people who know about those communities (Topic 7).	PPIE Committee
7	Consider education about how and why animal models are used and how we would like to reduce that in future (Topic 18).	Management Group

Appendix A - Open Space Topics

1. How to get Multiple Sclerosis (MS) patients involved in my project (recruitment, communication etc.)?
2. How to strategise PPIE?
3. What do charity partners want to see in PhD students to make them better at patient interaction?
4. How can PhD students get involved with PPIE in established projects (without it feeling like an afterthought)?
5. How do we make science more visible? / What do patients think about how science/research is shown e.g. in media? / Will patients look at our websites & twitter or is there a better method for us to do public engagement e.g. for Twitter content, blogs, 60 second videos?
6. Emphasis between the science or the hopeful outcomes of the research
7. Pros and cons of using a lateral flow test (specifically, reading it) and of having a vaginal/cervical swab?
8. Patients on the decision-making committees of the CDT?
9. How much trust would you have in modelling data that does not involve animals, either computational or in vitro (cells on a dish)? / Would patients/public trust research happening in humanised models compared to animal models?
10. How can we best involve patients experience/perspectives in medical device design?
11. How to improve patient engagement in research? What are the barriers?
12. How can we explain to the public ways in which their charity money is used?
13. How can patients of niche groups e.g. Brachial Plexus Injuries raise their need for research to funders/PhDs?
14. Would patients prefer to become research subjects earlier in the research pathway if it might lead to earlier identification of treatments, albeit with greater possible risk?
15. How patient samples e.g. bone marrow are used for research and utilised in the research lab? / Would patients be opposed to researchers using their own samples (cells, blood, other fluids)? Also, if these cells were to be commercialised?
16. Sensitive/inclusive communication with the patients
17. Would you eat lab-grown meat?
18. Patient understanding of the ethics of animal models?
19. What are some challenges you'd want to address in osteosarcoma research?
20. Research into wound/burn healing in limbs with nerve damage
21. What form of engagement is most effective?
22. What are the current and next-generation treatments and diagnostics for infectious disease?
23. Are lay summaries effective? Do the public read them or should we communicate in a different way?



24. Do the public or patients ever feel spoken down to or patronised when engaging with researchers / clinical staff – feelings of being a burden due to cost?
25. Have patients since/during treatment gained more of an interest in science / had charity pursuits?
26. How can small charities with no paid staff influence / find out about relevant research?
27. Arthritis – How to make research papers more accessible and understandable to general public?
28. What next for CDT PPIE?
29. What are current therapies for blood cancers, and how are we improving current research and therapies?
30. Should researchers engage / speak to patients with the condition they are researching as a mandatory part of PhD?
31. How do we improve patient access and student interest in “real world studies” integrating drugs such as chemo with synergetic treatments such as oxygen therapy or circadian rhythms to improve outcomes and reduce side effects? (Not discussed)
32. How would you like to use PhD students as a resource?