CROSSONER MARINES SERVICES

Workshop report

WAYS OF SEING INVISIBLE ILLNESS

22nd November 2021

Organised by Dr Michael Pierre Johnson, Gaston Welisch & Elio Caccavale
Innovation School, The Glasgow School of Art
in collaboration with Dr Margaret Rose Cunningham,
RSE Young Academy of Scotland









INTRODUCTION

This Crossover Workshop brought together a broad range of academic and disciplinary expertise and interests to explore new ways of seeing and understanding people's experiences living with and working with invisible illnesses.

It partnered with the Royal Society of Edinburgh's Young Academy of Scotland (YAS), recruiting academic members interested in developing patient-centred collaborations in response to the challenges of intangible health conditions. This initial group of YAS members identified challenge contexts they wished to explore based on their areas of research, which were then used to recruit further expertise from medical sciences, primary care and design to develop ideas through design activities.

At GSA, we suggest that innovation occurs at the edges of fields of expertise. As such, we feel that initiating design and science dialogues can reveal the matters of concern and opportunities in unfolding scientific advances.

The Innovation School at GSA aims to apply design practices and inquiries, in collaboration with contextual experts and the people affected across society, to bring tangible form to the abstract and complex contexts, such as scientific research, and its implications.

ACKNOWLEDGEMENTS

We would like to express our gratitude for the support received by the Biochemical Society. In particular, we would like to thank Dr Pedro Ferreira (Education and Public Engagement Manager) for giving us the opportunity and confidence to set up and develop the Crossover Project.

We are also enormously grateful for the contribution of Dr Margaret Rose Cunningham from the University of Strathclyde and member of the Young Academy of Scotland. Her energy, enthusiasm and guidance has enabled exciting connections and opportunities for design innovation to enhance what is possible for YAS members' research and impact.



BACKGROUND

This work has built on an original Crossover Workshop collaboration in November 2019 between the Innovation School and the Biochemical Society to explore the potential for exchanges between design and biochemical sciences. A video and downloadable PDF (link at end of document) capture the experiences and outcomes from bringing together eight biochemical scientists and eight design researchers to share their research interests and forms of disciplinary inquiry.

We have since been funded by the Biochemical Society and the Royal Society of Edinburgh Young Academy of Scotland to pilot three further Crossover Workshops programmes that bring together scientific, societal and creative storytelling disciplines from a core cluster of Glasgow-based academic institutes with national and international publics, experts and institutions.

The first workshop explored storytelling and visual ethnography to merge stories of people who work with, or are affected by, mitochondrial research and diseases. The second workshop partnered with STEM Equals to support the co-design of a programme of sustainability education days for young people with disabilities, their families and carers at Dolphin House, Ayr, during the summer school break in 2021.

Dr Margaret Rose Cunningham attended our original Crossover Workshop and was a vital part of bringing together (and participating in) the STEM Equals Crossover Workshop. Margaret has been our direct partner in approaching and bringing together members from YAS for this third Crossover Workshop and we anticipate many routes for collaboration together going forward. She also secured additional funding from the Physiological Society for public engagement on this work.



Elio Caccavale

Reader in Transdisciplinary Design Innovation
The Innovation School, The Glasgow School of Art



My research investigates design and science partnerships, with particular emphasis upon collaborative research methods. Furthermore, it explores new visual and three-dimensional design vocabularies for thinking about ethical and social issues in the sciences, and it aims to contribute to the ongoing methodological debates in bioethics, science communication and the sociology of emerging scientific knowledge. My research projects have featured prominently in national and international exhibitions (MoMA NY, Dana Research Centre, Science Gallery Dublin and Royal Institution) aimed at increasing public understanding of design's interface with science and society, and introducing new design ideas, methods and approaches to the public.

My aim with the Crossover project is to create a dynamic network of transdisciplinary dialogue about science and society, facilitated through design innovation, to enable consistent crossover between different disciplines and a range of institutions, within the academic community, the public and the third sector.





Dr Michael Pierre Johnson

Innovation Leadership Fellow in the Creative and Digital Economy The Innovation School, The Glasgow School of Art



My research uses design practices, such as visual mapping and modelling methods, to support and evaluate creative collaboration between different expertise, stakeholders and publics in the face of shared societal challenges. In Jan 2019 I was awarded an AHRC funded Innovation Leadership Fellowship in the Creative and Digital Economy. By combining sociological theory with design practices and qualitative modes of analysis, I apply Design Innovation to support reflexive discourse on the value of creative collaboration and innovation.

My aim with the Crossover project is to support the design and evaluation of effective ways for science, societal and creative disciplines to come together, collaborate and make a difference, as well as evidence how 'transdisciplinarity' - a practice that transcends, challenges or renegotiates traditional disciplinary boundaries and reconstructs them in new positions - can be said to take place.





Gaston Welisch

Research Associate

The Innovation School, The Glasgow School of Art



My practice focuses on incorporating Play into our interactions with everyday objects and environments. By combining different mediums and platforms, I aim to communicate complex topics and problems in engaging ways.





Dr Margaret Rose Cunningham

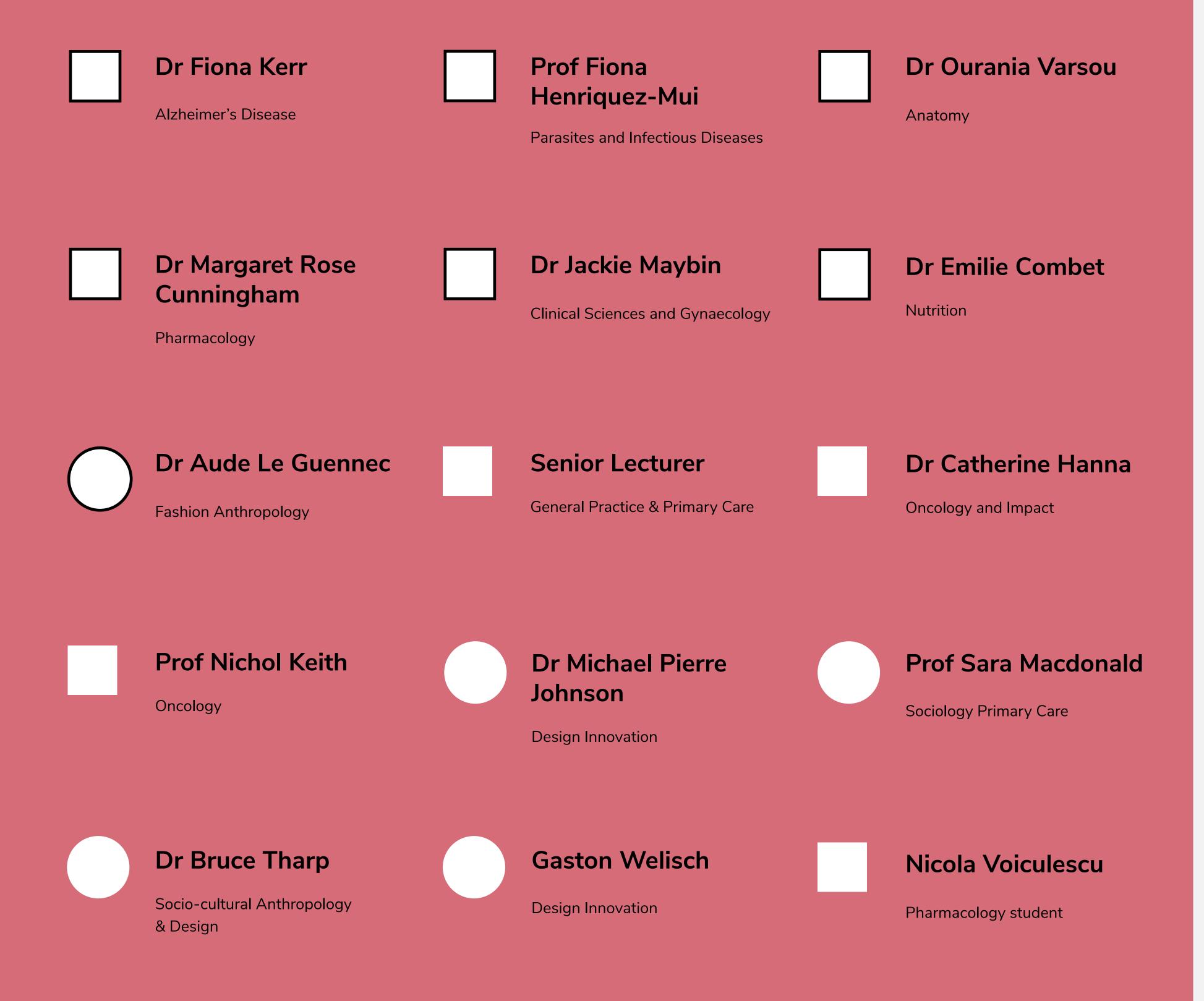
Senior Lecturer in Cardiovascular Pharmacology Young Academy of Scotland, Facilitating Group

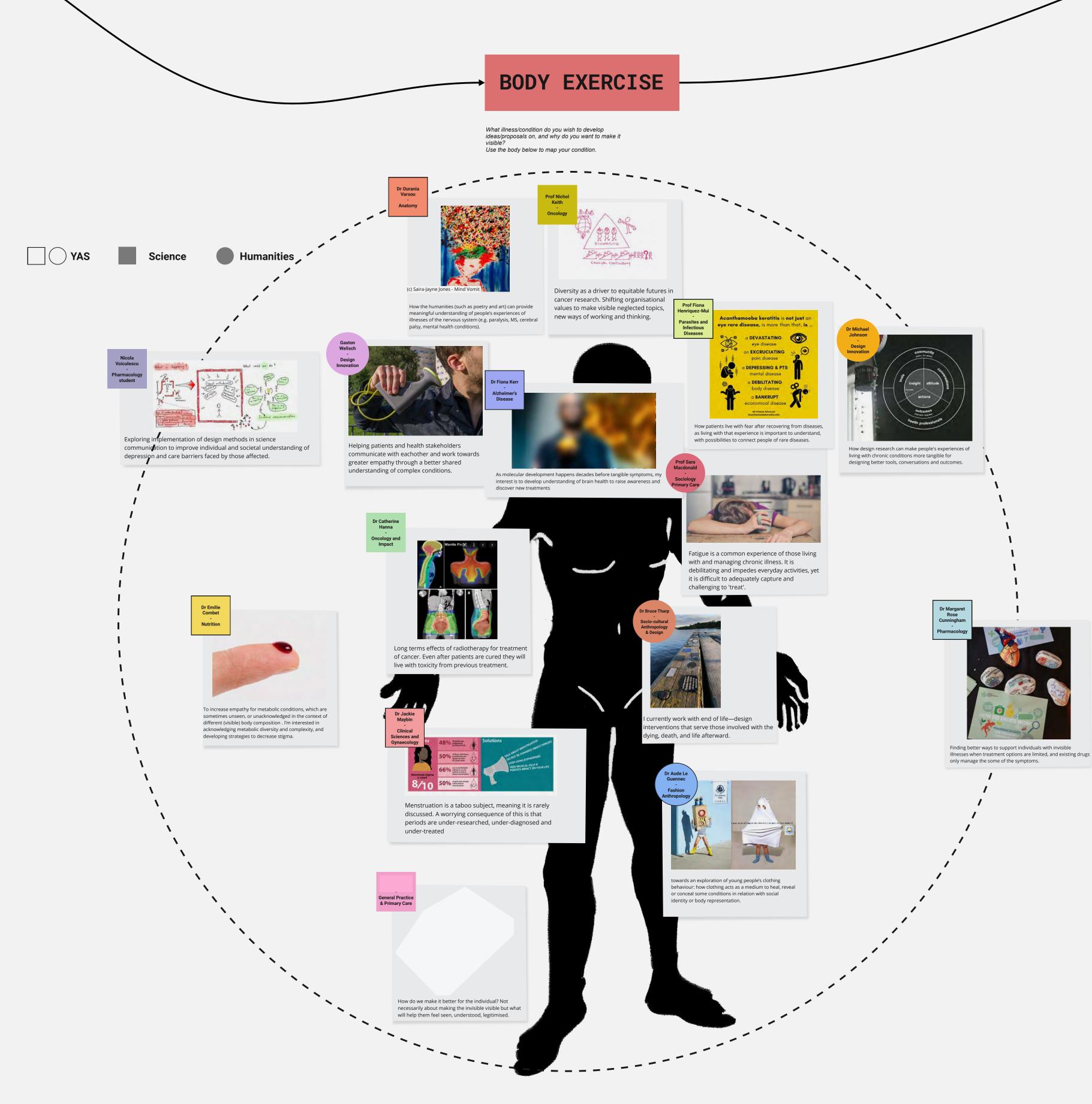


When the Crossover project between GSA and Young Academy of Scotland (YAS) was initially designed, we set out to provide YAS members and other participants with new transdisciplinary learning opportunities and applications of "crossover" knowledge for new project idea generation. In doing so, we wanted to develop a range of societal-facing project proposals that incorporate methods of design innovation to reach diverse audiences and maximise impact.

The ethos of YAS is to work together to address the most challenging issues facing society in Scotland and beyond. The impact of Covid-19 and health inequalities borne from disruption to regular healthcare services and access to valuable support networks represents a priority area that warrants immediate action. With this workshop, we managed to engage in rich discussion across expert groups to identify key challenges that exist in this space and create clear actions to enable better support mechanisms to empower those living with unseen illness. These core areas will form the basis of continued engagement, where YAS expertise can meaningfully contribute towards amplifying the voices of those most impacted by invisible illnesses.

LIST OF PARTICIPANTS





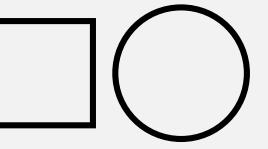
The following symbols were used to clarify the background of each participant:



Science



Humanities



YAS

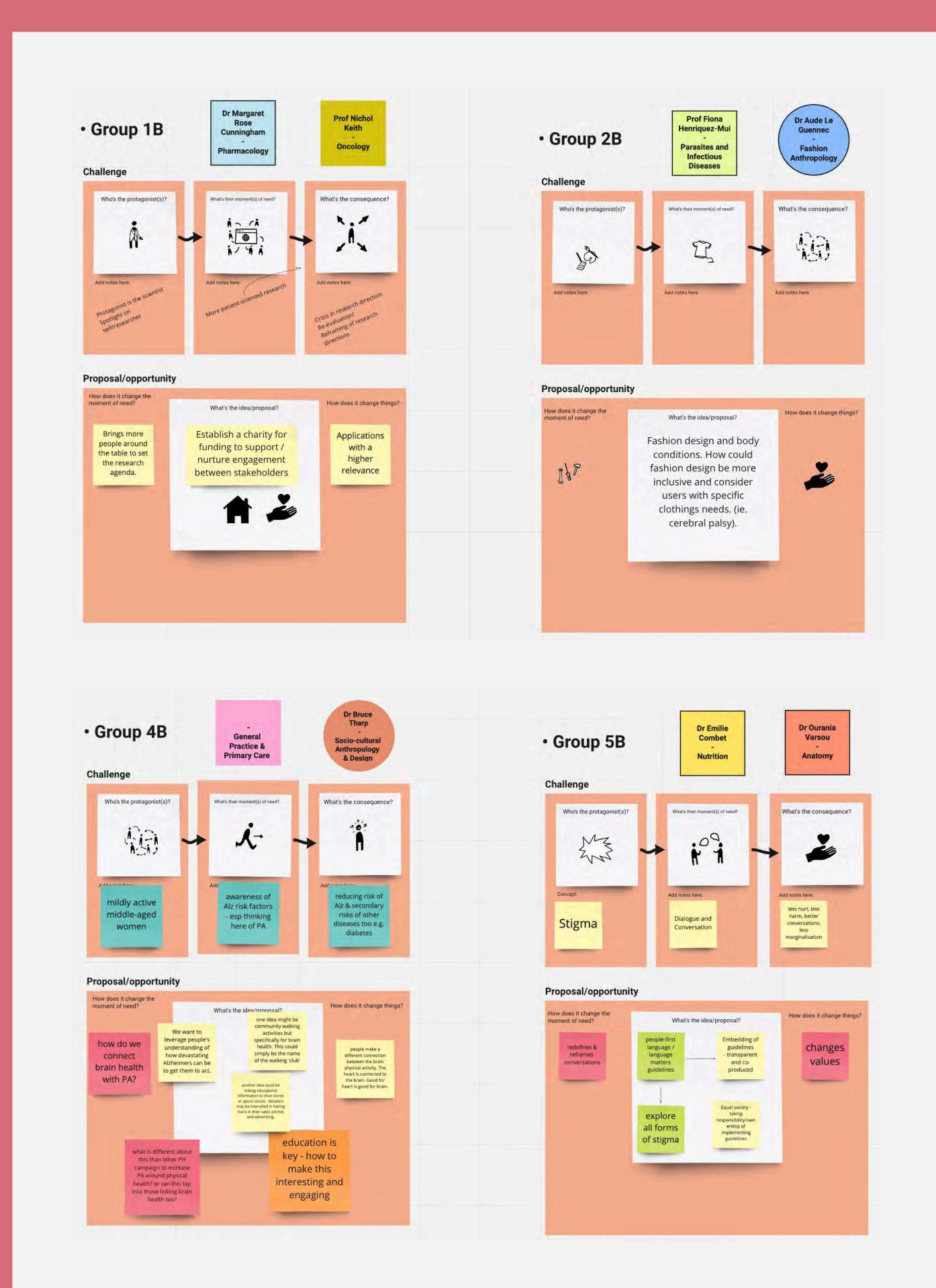
WHAT DID WE DO?

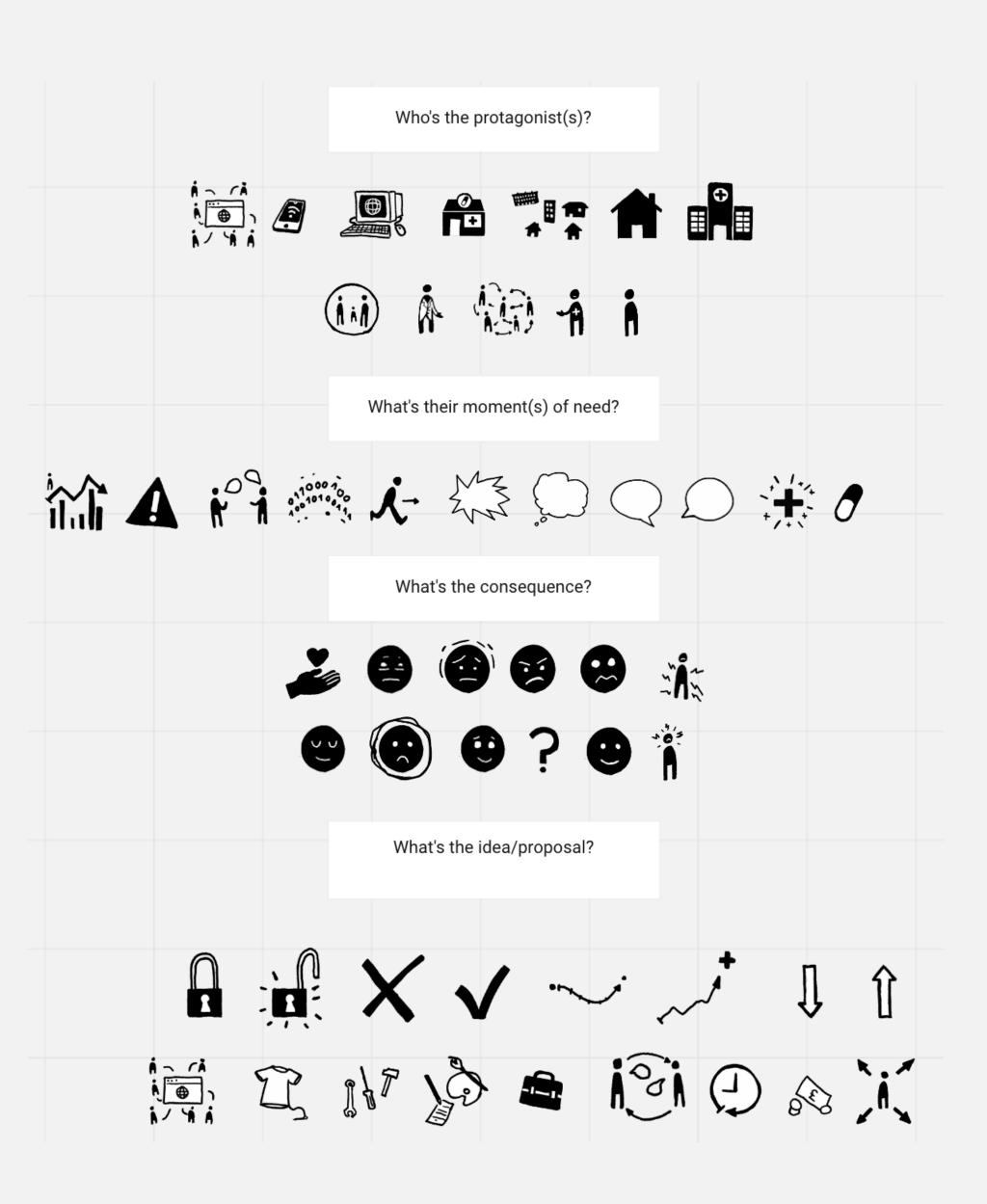
On the 22nd November 2021, 15 participants with expertise ranging in pharmacology, oncology, anatomy, alzheimer's disease, primary care, gynaecology, infectious disease, nutrition, anthropology, fashion and design were brought together to participate in a workshop exploring ways of seeing invisible illness.

Each medical academic participant was asked to present themselves in 2 minutes using an image and a short statement on what illness they wanted to make tangible and why. Other participants presented how their discipline contributes to making the intangible tangible.

Participants were then put into pairs of contrasting expertise to identify and storyboard a scenario or challenge they wish to change. Then together they would sketch an idea or proposal for how it could be positively addressed.

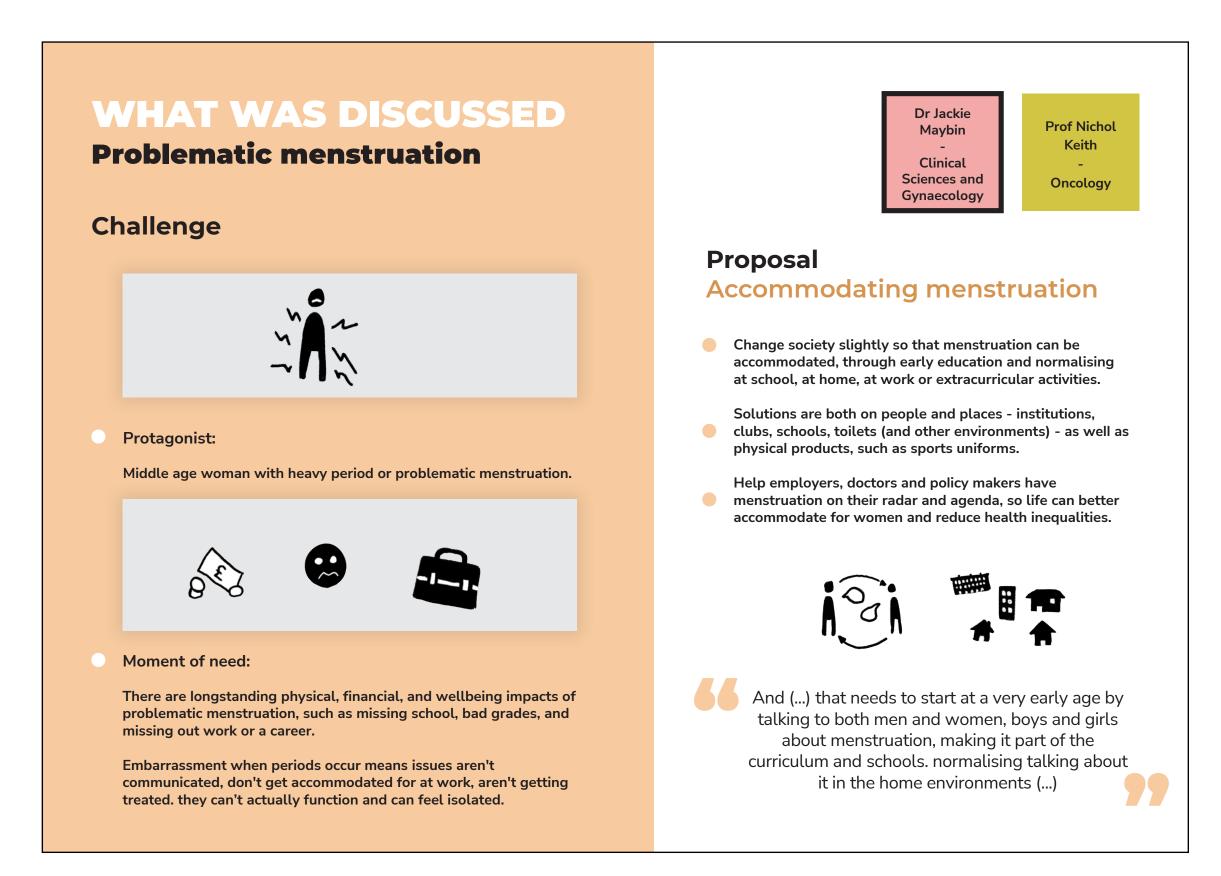
Two sets of pairings were given this task, with 14 proposals drafted altogether and shared for wider feedback on key strengths, opportunities and next steps.

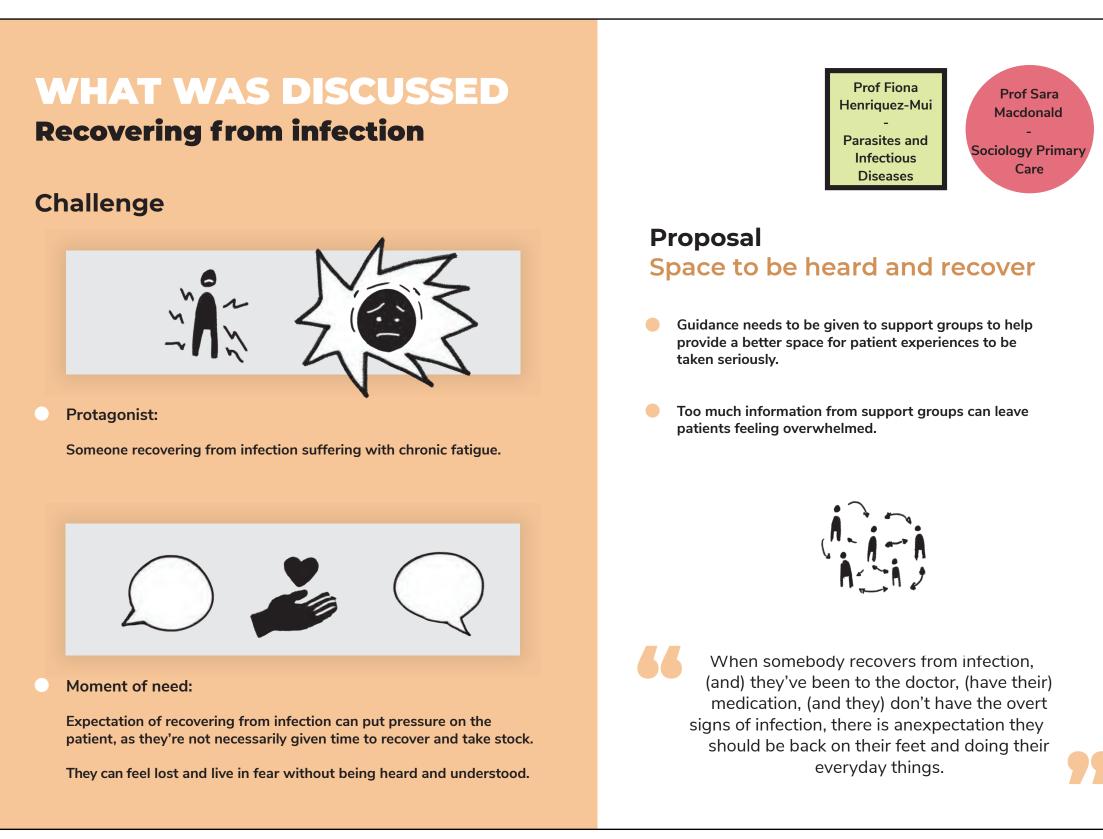




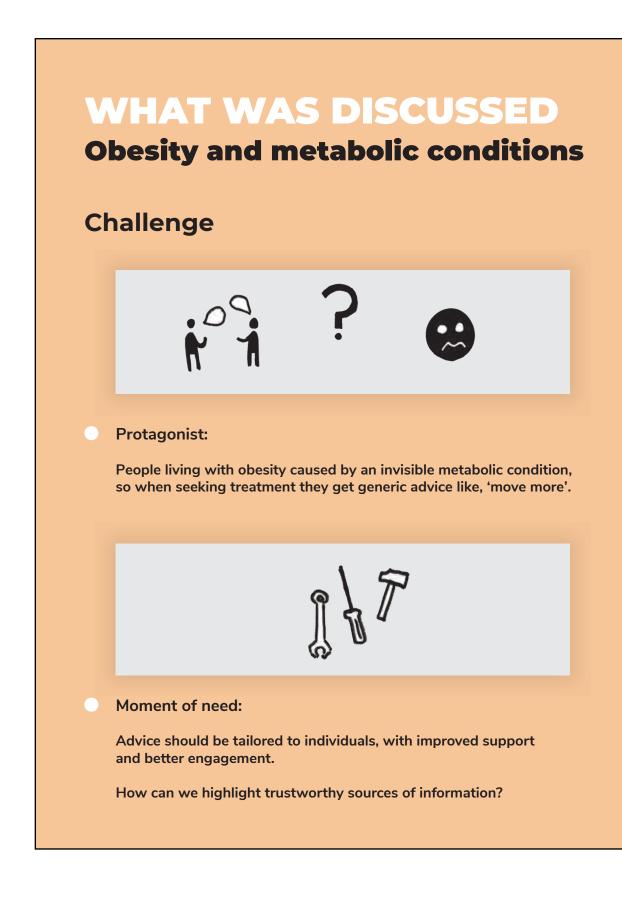
WHAT WAS PROPOSED?

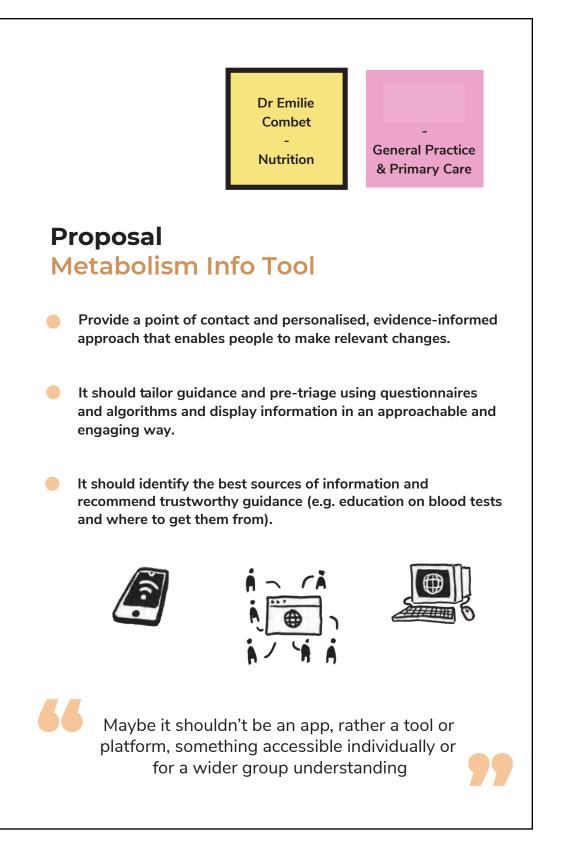
STIGMA & EMPATHY

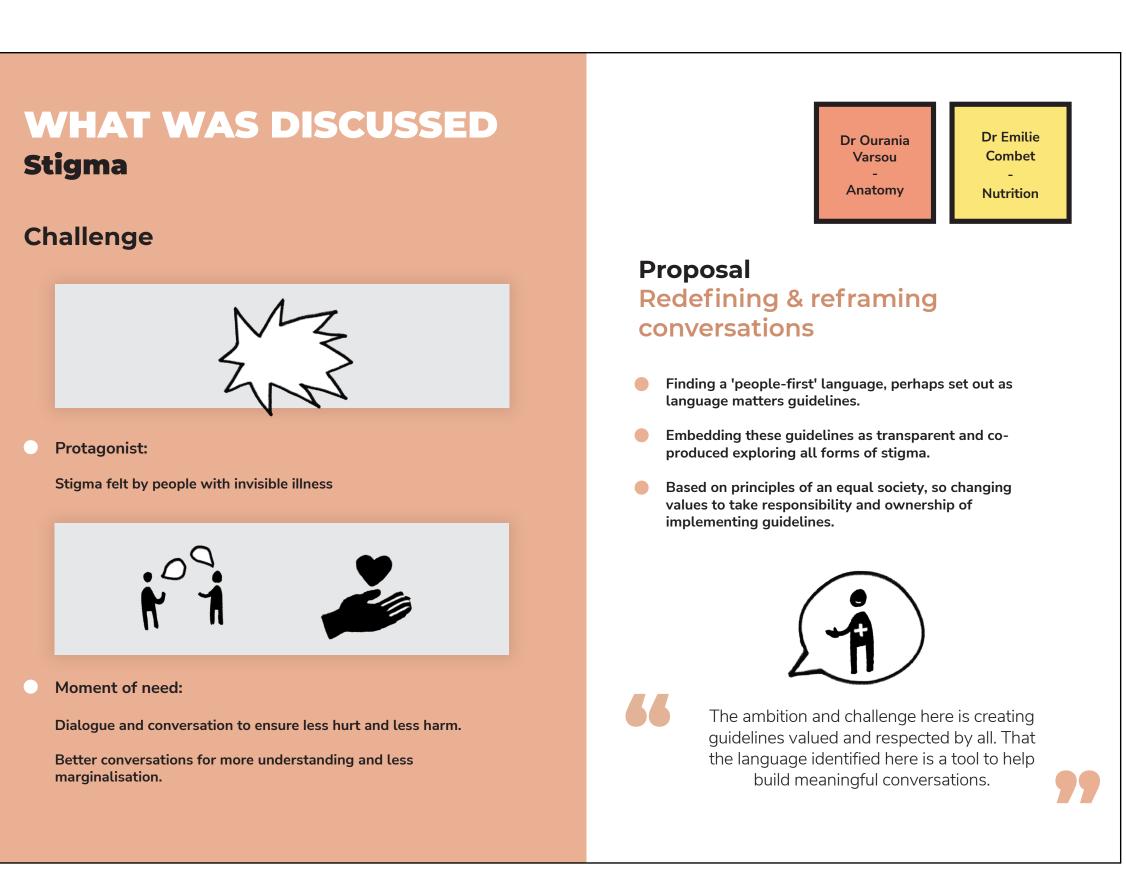








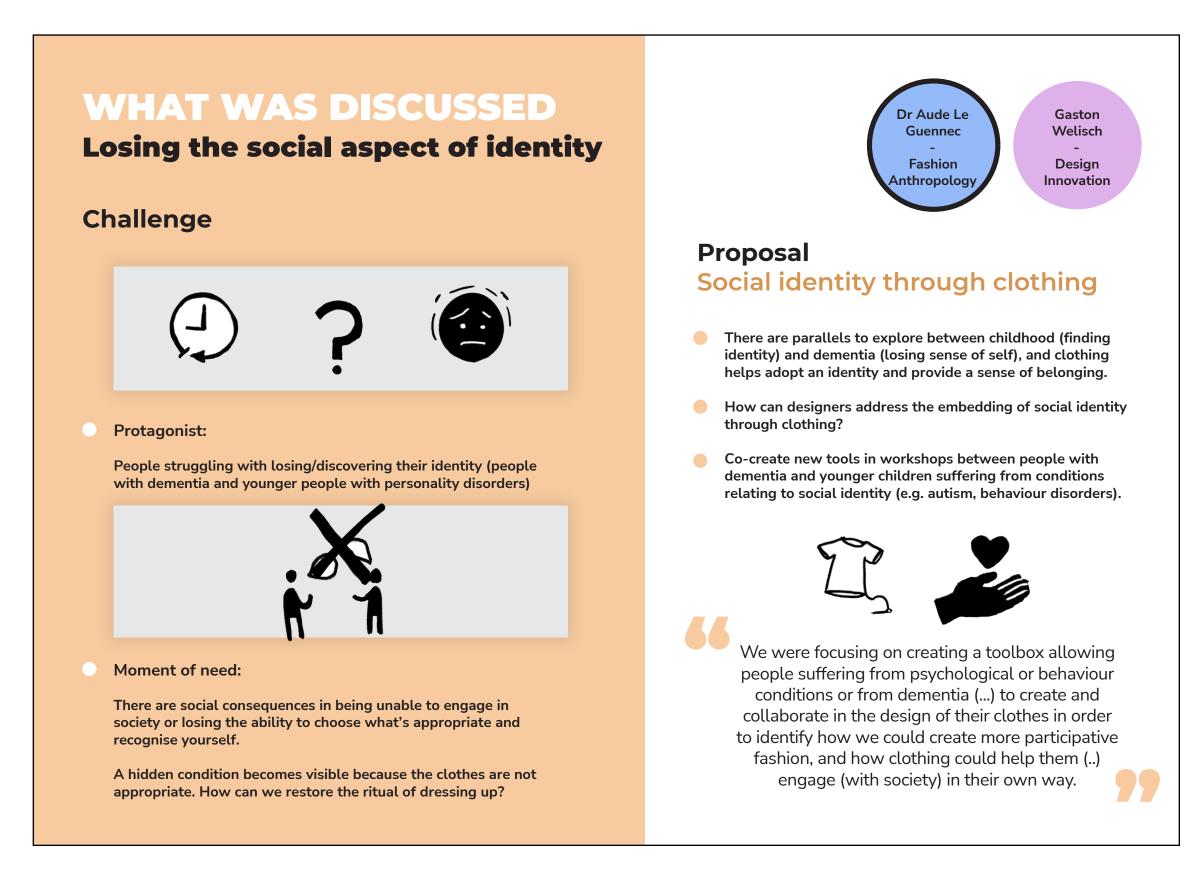




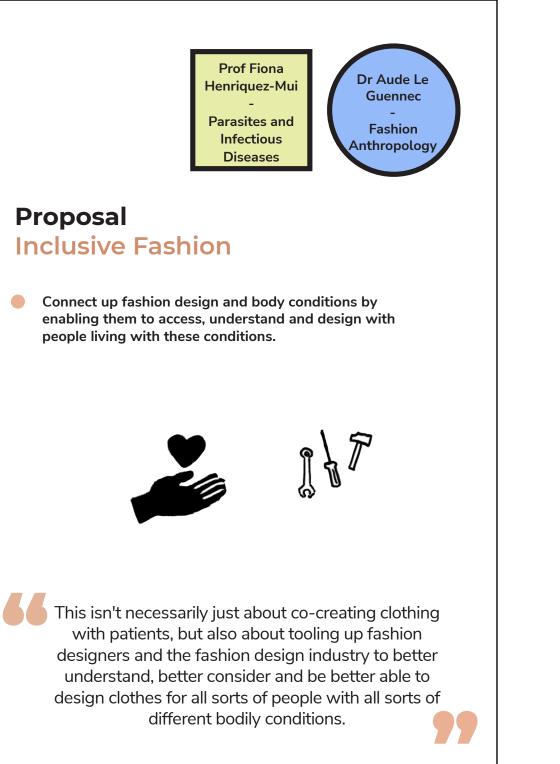
Summary

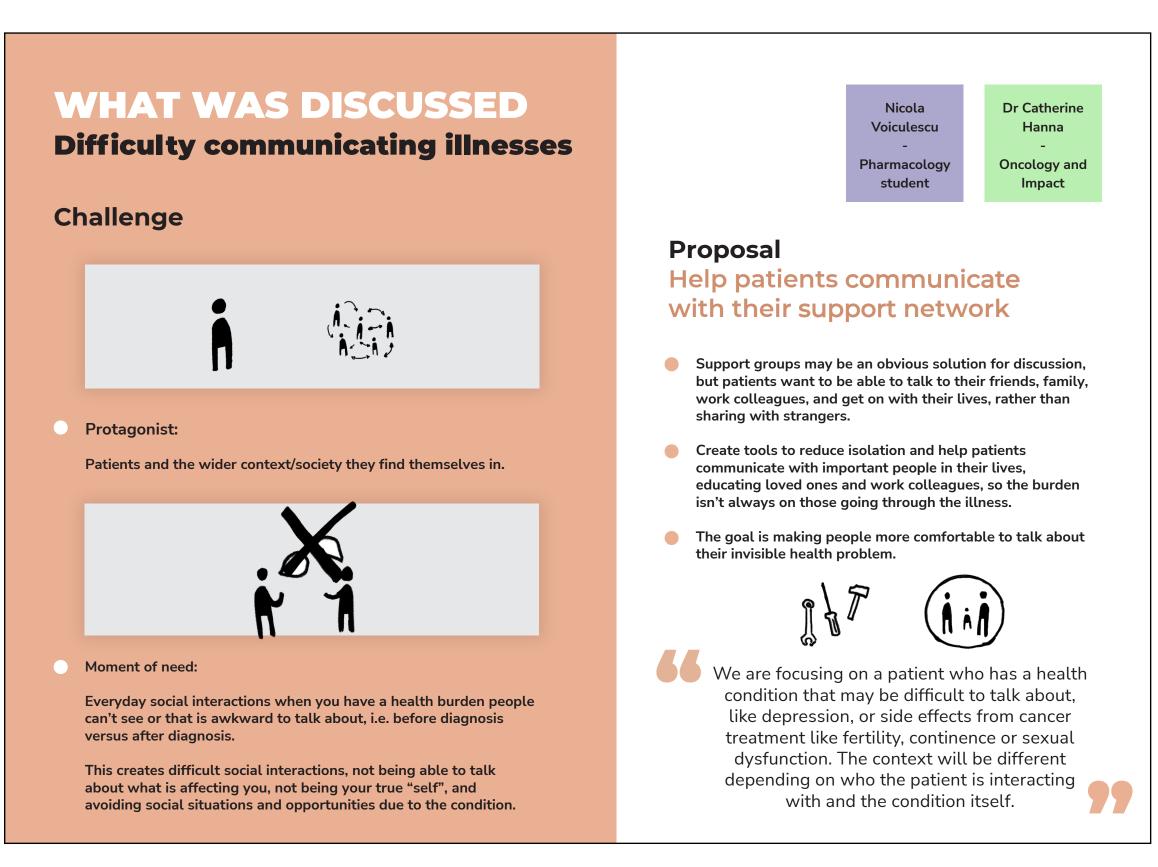
A core theme throughout the process and workshop discussions was the challenge of stigma for those affected by illnesses for which there was a lack of wider understanding. This spanned mental health, rare diseases and common disorders, though all seem to call on similar needs and responses for language, processes and tools that enable greater empathy. Therefore, we aim to further understand the commonalities and differences in the experiences of stigma across multiple invisible illnesses.

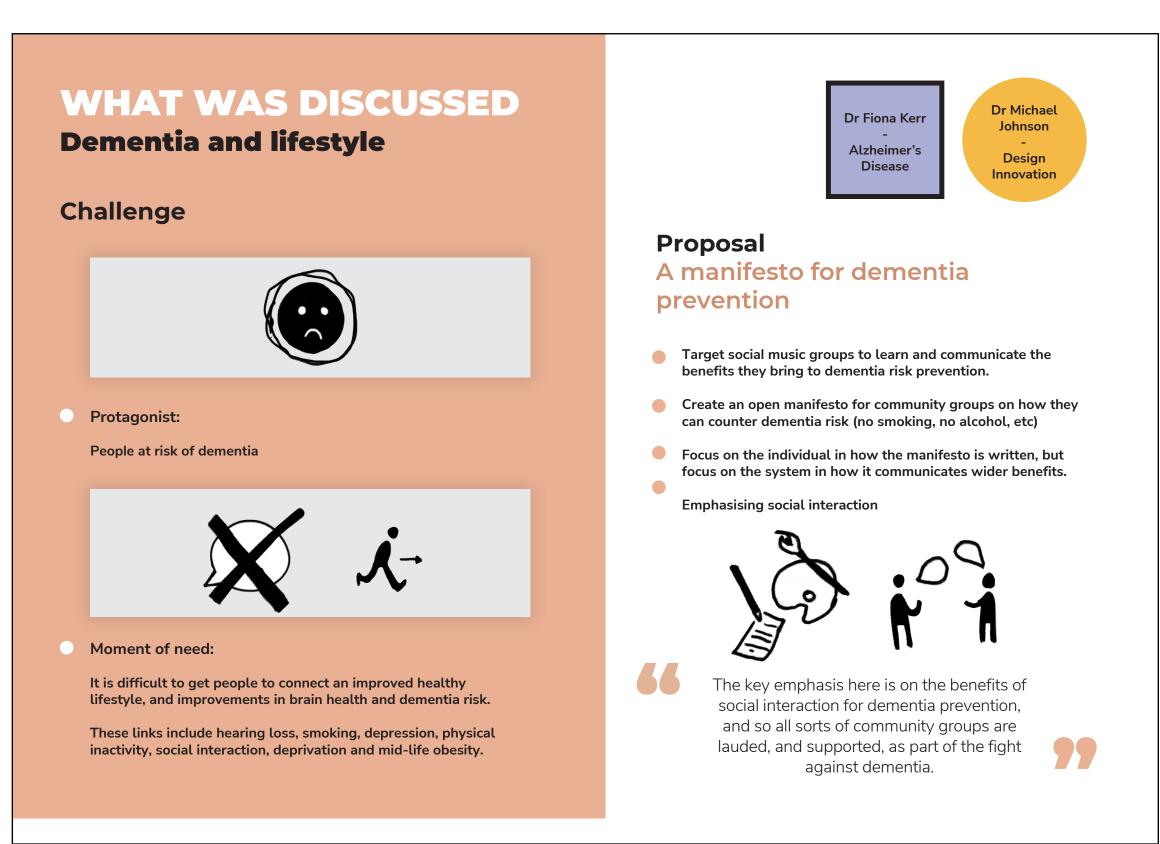
WHAT WAS PROPOSED? POSITIVE SELF-IDENTITY







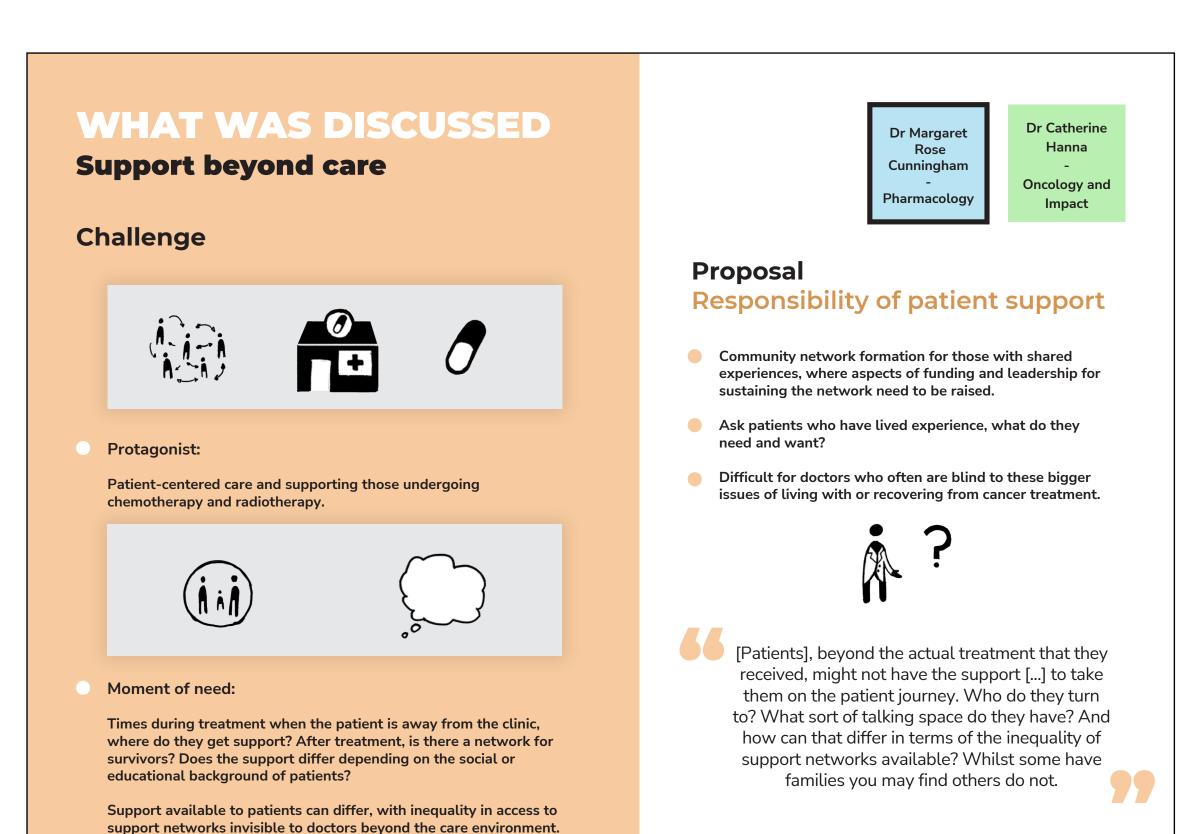


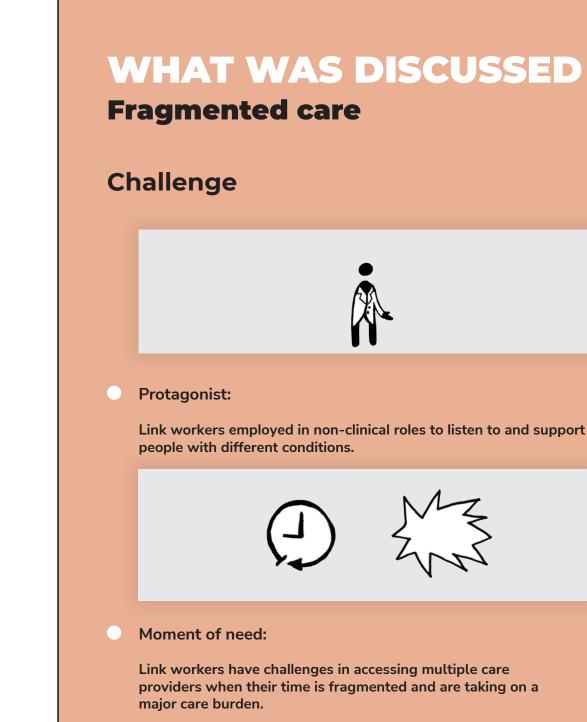


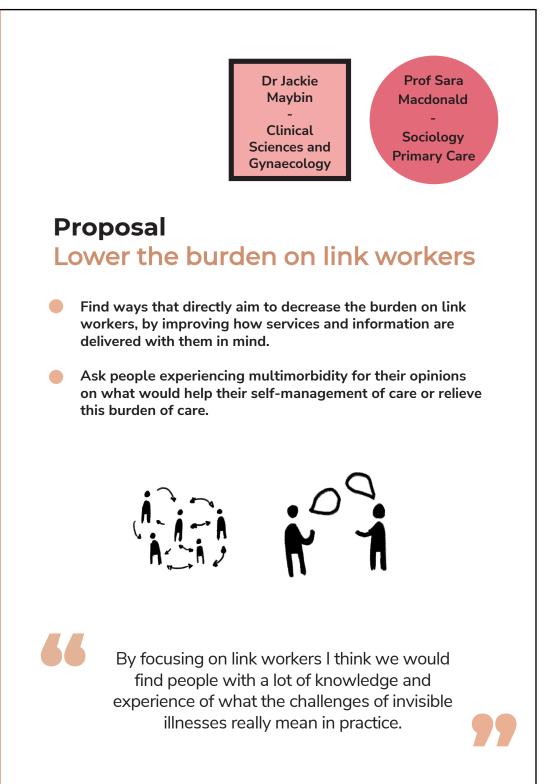
Summary

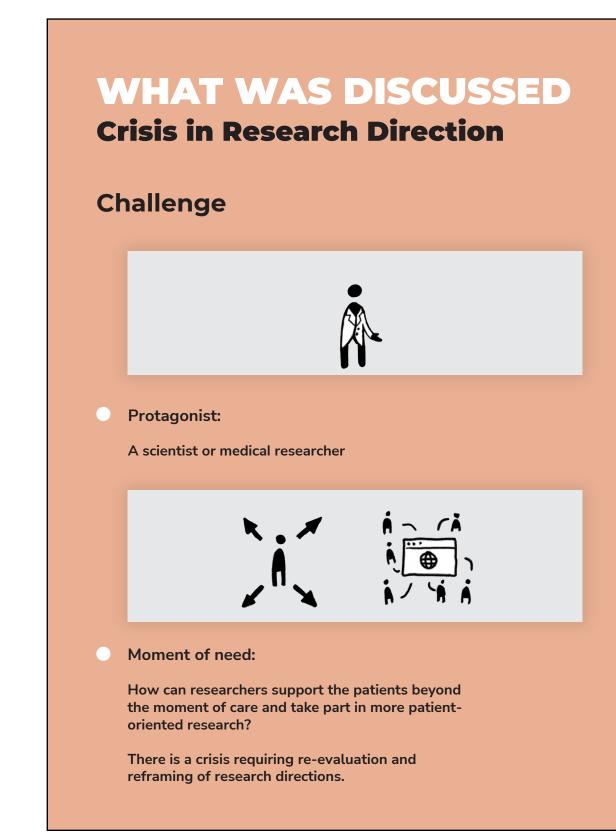
Alongside the recognition to address stigma through better public understanding were ideas seeking to empower individuals living with invisible illnesses. Participants explored in what ways patients could positively express identity with their conditions, with potential for this to ease how they help their support networks and clinicians understand their experiences. We aim to pilot what such an approach can look and feel like through wearable items.

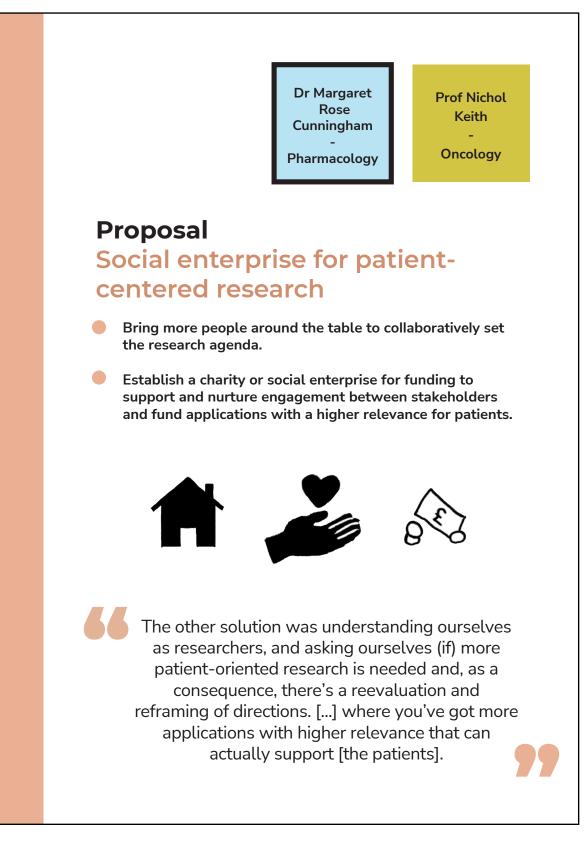
WHAT WAS PROPOSED? DISTRIBUTED SUPPORT

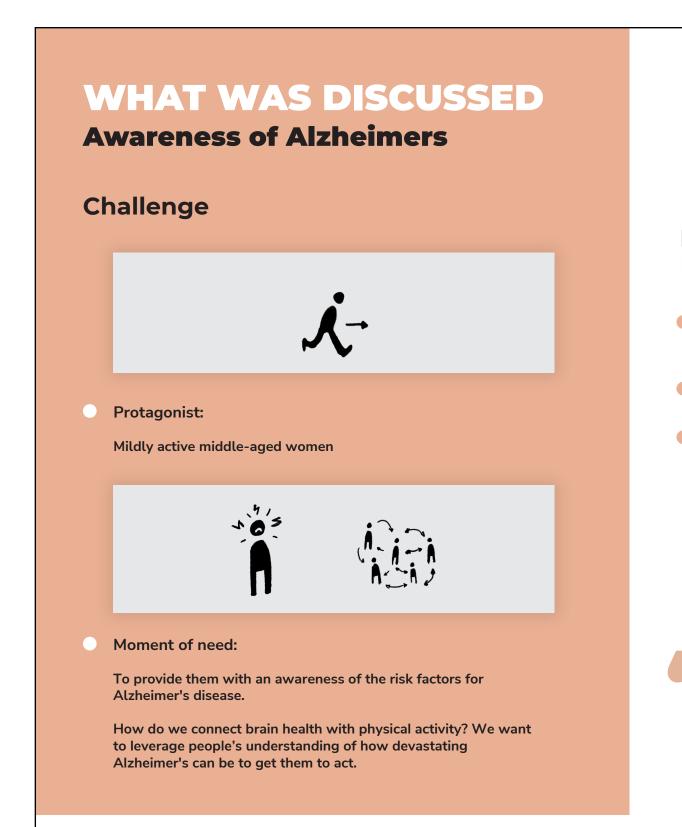


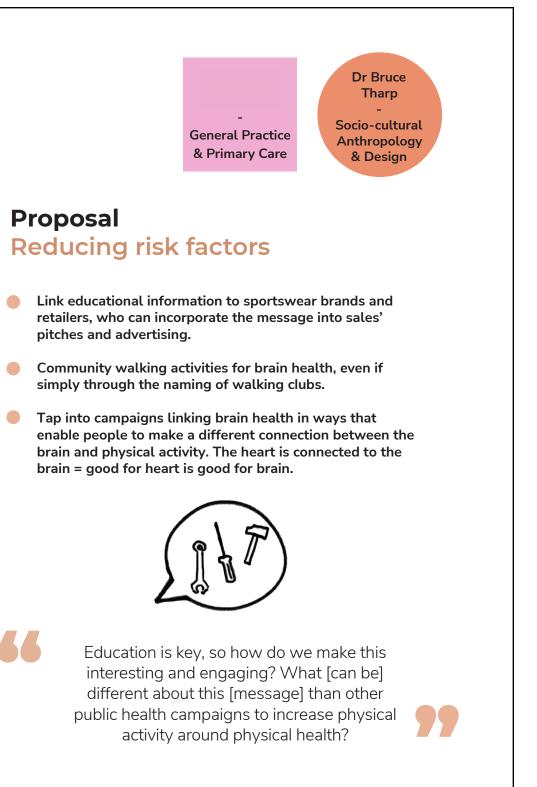


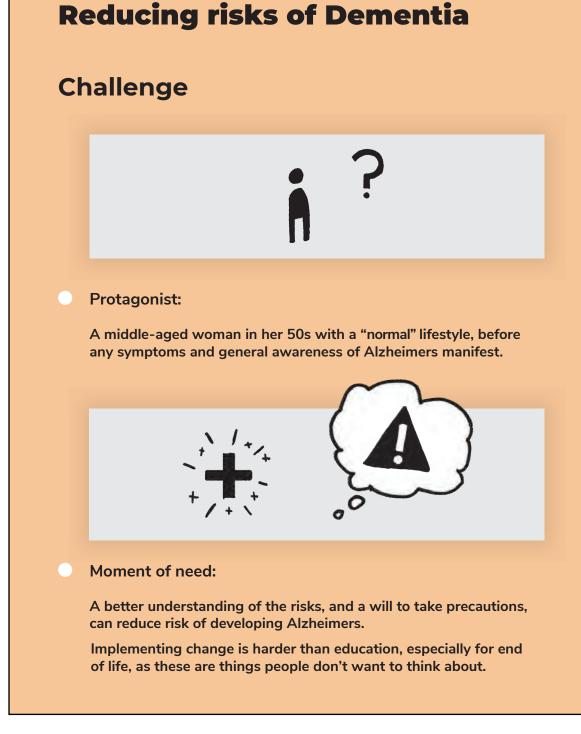




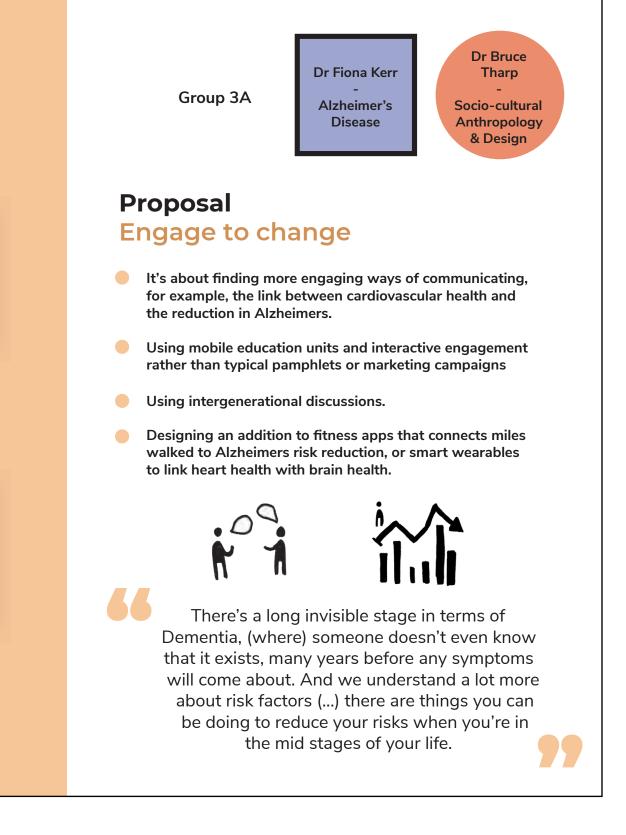








WHAT WAS DISCUSSED



Summary

There was common acknowledgement of a lack of joined up thinking for patient-centred approaches across medical research, clinical services and support networks. Siloes or gaps were identified that place a burden on existing support services or left patient needs unmet. We aim to explore how partnerships and coproduced services across these siloes could add enormous value to the patient journey when coping with invisible illness.

WHAT'S NEXT?

The opportunity to bring such a valuable range of expertise, insight and disciplinary know-how together on this important topic of invisible illnesses has enabled us to identify opportunities for impactful collaboration. We aim to commission design-led briefs addressing these areas, inviting workshop participants to contribute, in order to develop mutual insights, innovation and tangible outputs for ways of seeing invisible illness, which will be used to release further funding for more substantial projects.

Stigma & Empathy

We would like to commission a videographer or audiographer to produce a video or podcast gathering interviews and insights on stigma & empathy across various invisible conditions presented through this workshop. Such a piece would aim to be public-facing, demonstrating how engaging patient voices can develop empathy as a route to change.

Positive Self-Identity

We would like to commission a fashion design student or team to explore positive self-identity in clothing for invisible conditions. This would bring design together with people living with invisible illness, and wider expertise, to explore and prototype what difference a self-expression through clothing can make.

Distributed Support

We would like to commission a service designer or team to prototype a social enterprise or charity that can collaboratively bridge research, clinical practice and support service siloes to innovate patient-centred care. This could focus on a particular condition for a pilot co-design approach, but would intend to learn how it could be applied across invisible conditions.



Relevant links:

More details about the Crossover Programme can be found at: https://www.gsainnovationschool.co.uk/post/crossover

The original Crossover workshop details can be found at: https://www.gsainnovationschool.co.uk/project/crossover-workshop

The Royal Society of Edinburgh Young Academy of Scotland: https://www.youngacademyofscotland.org.uk









