

Please provide us with a summary of your PEARL Grant project, how it went and what the impact was using the framework below as well as adding / attaching any additional information or outputs you feel relevant.

Activity Title:	Madness, past & present
Grant-holder name:	Robert Goemans

- 1) Please provide a summary describing the final project as it was delivered. Include details of when and where the activity took place, and any changes made to the original proposal alongside why these took place.

The Lincoln Lunatic Asylum (LLA) Project is a cross-college research group at the University of Lincoln involving staff from the School of Health & Social Care and the School of History and Heritage. Its mission is to analyse current practice through a sociological understanding of the past. The LLA was opened in 1820 and became the first asylum in the country to achieve total abolition of mechanical restraint in 1837. Through an analysis of the original documents we are seeking to understand how the construction of identities, including conceptions of gender and class, influenced how people's madness was constructed and experienced.

We applied for PEARL funding in order to run an event where we would be able to capture the responses of people with experience of mental illness to our research. This is a unique opportunity to develop democratic research that is shaped and focussed by people whose life experiences or interests make this an important subject for them. We hope to be challenged on our research and to consider new ways of understanding the human experiences which we explore in our research and to bring people's experiences from 2 centuries ago to life. Normal conferences usually have a one way flow of information, from presenter to audience. We hoped this event would capture the analysis and insights of the attendees' responses to the presented material, enhancing this material with additional benefits of live experiential and reflective input. The researchers hope to use this additional input to provide a unique perspective on their research and develop new, user-informed, avenues for analysis.

The 'Madness past & present' conference took place on the November 18th 2019, at the Blue Room, in The Lawn – the original ballroom of the Lincoln Lunatic Asylum. 100 people had registered to attend via Eventbrite, and 60 attended on the day. Break down of attendees is as follows:

	yes	no
Problems with own MH	20	13
Received services	16	8
Worked in MH	21	12

Age: 30s – 5 / 40s – 4 / 50s – 9 / 60s – 10 / 70s – 3 (no response – 2)

Gender: Female 23 / male 5 (no response 5)

During the day, four research presentations were given (see below), as well as a final plenary, and activities for generating feedback from attendees in response to the research presented took place alongside these. An additional room was used where people could reflect on or discuss the presentations with the presenters, and flipchart paper and post-it notes were provided for people to record their thoughts. A questionnaire was provided, and people were also invited to record their feelings on camera. Additionally, two of the presentations involved group activities which produced additional feedback.

The presentations given on the day were as follows:

1. Introduction: Rob Goemans, University of Lincoln
2. Keynote: The impact of institutionalisation on families of Broadmoor patients - Jade Shepherd, University of Lincoln
3. Session 1: Serendipity and archival research or 'reading between the lines' – Anne and Val Reed
4. Session 2: Researching the history of old hospitals, problems, challenges and issues – Michael Ferriter
5. Session 3: The abolition of physical restraint at the Lincoln Lunatic Asylum – Nigel Horner, University of Lincoln
6. Plenary: all presenters

- 2) Assess the outcomes of the activity and its impact on people who engaged with it. Please include details of;
- a. What was successful?

The project team considered the day to be a very positive success: the conference was well attended, informal and formal feedback was positive, attendees engaged well within the sessions and with the feedback tasks, and sufficient material was gained through the feedback tasks in response to the research and the issues presented.

- b. What did not go so well?

Of the 100 people who booked onto the event through Eventbrite, only 60 attended. I was aware of people who wanted to book on but the numbers were limited to 100 (which was the most the venue could hold). I emailed attendees prior to the event to ask people who could no longer attend to cancel



their tickets, but on the day there were still people who would have come but who didn't because of the ticketing process.

c. What would you do differently next time?

As per the point discussed at 'b' above, I would have made more tickets available despite the risk of being oversubscribed and would have communicated with potential attendees more frequently prior to the event to ensure sufficient places were available.

d. What was the impact? Please include a summary of how many people have engaged with the activity (face-face, online, via social media etc.). Include any qualitative or quantitative evaluation data and comments.

40 evaluations were returned (67%) and these rated the event as follows:

Very poor	0
Poor	0
Average	4
Good	17
Excellent	16
No rating	3

Comments on the evaluations (Q6: 'whats the main thing you'll take away from the event?') included the following:

- The information provided has been informative and thought provoking. I will be looking at Being Human website to find more info
- That learning from the past should help to change the future. Perhaps we need to relook at our baseline
- Mental health is such a wide topic. How mental health crosses over the generations – love to know more
- A desire to know more about historic madness
- Interested to learn more about such events
- I will be looking to move into an employment role within the mental health service
- I learned a great deal from today & that things haven't changed much in mental health over the years from 1820 to the present
- New take on usefulness of research
- Would like to research more into the history of mental health institutions in Lincoln
- Ideas around the ethics of research including confidentiality and consent
- Ways to organise research dissemination events ("community science") for my own work. Also this event made me reflect on the link between past and future & showed how linked and similar issues we face are + learned of some historic events in Lincoln.
- To continue to discuss mental health to help reduce stigma & find the most appropriate support for people.





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- 3) How has your public engagement activity had an impact on research? This could include new data, new questions generated by the public, how the engagement has changed or shaped your research etc.

We have collected a lot of data through the event which captures people's responses to our research as well as links they have made between historical and contemporary approaches to mental illness. This includes specific issues (such as confidentiality and historical data, is it ok to name people from the past?) and general issues (do people think this kind of research is important?). Much of this material is still to be analysed, but will help provide important context for our research as well as providing support and justification for the continuation of our research and the themes and connections we have identified.

The main focus of the questionnaire which attendees were asked to fill in was on the similarities and differences between historical and current mental health care. While an analysis of these responses has not yet been completed, reading through the questionnaires there is a clear consensus that many issues faced by people with a mental illness in the past are still causing problems today:

- Many aspects are the same – patient family isolation/deprivation/physical ill health. Lack of support for families
- In many respects in the 19th century, kindness and attention to individuals was greater
- It is still marginal in health care terms and still largely stigmatised
- That families relatives and friends are emotionally at risk too – but there is little or no mechanism to remedy this
- It isn't understood. Causes/triggers seem to be so variable & many seem to be entrenched in hardcore socio-economic issues that have been too big for successive governments to handle, let alone cure.
- Still often seen through the medical model of care – how much have we really moved on?
- An understanding that MH problems are interior/intrinsic to the person rather than primarily understood as relational or socio-cultural
- Dominance of "expertise" principally that of medicine and psychology
- Nothing changes
- Still how MH is viewed is seen as a problem – if people don't fit in what is the norm?
- Restraint still happens and leads to death – physical and drug restraint
- Patients and their families have always suffered as a result of their diagnoses – their personal situations are the same now as they were then. These stories were just of people living their lives and coping as best they can/could. There are more similarities than differences
- Looking for an easy answer. Historically this could have been to lock people away. Now it can be to issue medication without due thought about the appropriateness and no review. Difficulty of having enough caring staff. Patients getting trapped in the system





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Responses did, however, also point out some areas where improvements have been made:

- It made me reflect on how much mental health care for schools has grown in last decade or so (formerly worked in very large sixth form college) Mental health is far more public in last decade
- Recognition of talking therapies, though access is still a barrier
- People are only hospitalised when necessary
- People are now wanting to discuss mental health issues, there were lots of people in the room from different backgrounds, some with lived experience – everyone wants to ensure that mental health is seen as physical health is and supported accordingly
- Challenges from survivor / user movement

4) Are you hoping to repeat, continue or carry out further activity following on from your PEARL grant? If so, please provide details.

Not at present, although there is the possibility that we may repeat this in the future. We will, however, be continuing the analysis of the materials produced at the conference.

5) Please describe any outputs from your project you could provide to support future PEARL and public engagement activities at the University such as;

- a. Photographs / films
Yes, we have photos, which we have already sent through to PEARL.
- b. Evaluation data
Being Human evaluations have been supplied to the PEARL office.
- c. Methodologies
- d. Contacts

6) Are there any further comments, ideas, suggestions or other you would like to share?

