

# Libby Fellowship Int Final

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## SUMMARY KEYWORDS

people, work, fellowship, impact, research, death, palliative care, ucl, systems, relationships, map, exploring, partners, dying, role, connections, discipline, experiences, hospice, relevance

## SPEAKERS

Libby Sallnow

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Libby Sallnow 00:00

My name is Dr. Libby cell note, I am a academic and academic in the UCL Marie Curie palliative care research department in UCL. And I've got a clinical role in the NHS as a palliative medicine consultancy and people at home in Camden and Islington, and also an academic role at St. Christopher's hospice. So I've got a kind of broad portfolio of interests really looking at death, dying and grieving from kind of clinical service perspectives all the way through to academic and kind of Public Health Perspectives. All my my motivation, really, for undertaking research in the first place is that I think it's a really important lever for social change. And I've been working in the field of new public health approaches to end of life care, or more social approaches to end of life care for many, many years. So trying to understand really how that works, in terms of beyond just professional services beyond service responses at these times, and so I can see the role that research has had. And I've always been interested in really what that means for real people, and leading to change. So I wanted to have the opportunity to explore impact, it being really one of the crucial parts of doing research through a kind of supported year long fellowship. And that was what was really exciting to think I'd be guided through to really understand that and some of the other one of the other key things that I was wanting to work through was to build connections across UCL is there's so many resources, people doing such interesting stuff across different disciplines. And I think the only way to meet some of the really, these really big, wicked or thorny challenges that we face in health, social care, and beyond, is through interdisciplinary work. But I felt a bit stuck about how to actually do that, how to make those connections and how to learn about other people's work. And then also thinking more broadly about what impact means. So I wanted to build these kinds of connection resources. And yeah, kind of an interdisciplinary approach within death and dying through Through this fellowship. So the project that I brought to the fellowship was to understand the real life impact and relevance of the Lancet Commission on the value of death that we had produced a series of commissioners from around the world, we had produced the Lance's Lancet Commission report last year. And this was really advocating a much broader response to death and dying, understanding the role and value really that death dying and grieving have in all our lives and in society. And the question is, it was a huge report 25,000 words many, many different recommendations alongside some really core principles that we advocated for. And as with all these things, the next question was, so what, and I wanted some time and support to really explore some of these implications. And the key question I was

hoping to address was, how can we understand the role of complex systems which are increasingly recognised as playing an enormous part in all our lives and particularly in complex social events such as death, dying and grieving? I wanted to understand what relevance what impact what implications looking at death and dying through a complex systems lens had. So did these read just these? This these principles resonate? Did they mean something? Did they bring something to the field, because that's what we've thought and suggested in our research, but we didn't know this in practice. So I began exploring this with our stakeholder partners, St. Christopher's hospice, which is a large hospice down in southeast London. And so we started in a series of different conversations, they've got a Community Action Team there who do a great deal of working with citizens and local people as partners, co producing new ways of understanding, caring for managing death, dying, and loss. And so we began exploring what they meant. And there was a huge deal of resonance, people really intuitively agreed that the topic made sense. And the using these ideas of complex systems really added a great deal of value into how we began understanding the challenges and barriers to good care and then the kinds of levers or opportunities. We are planning some focus groups within one specific geographical area within one borough where we're going to be using an artist to map using creative methods to map these complex systems, using the stories of real people to say this is actually what happens when you're faced with a terminal illness or when you're caring for someone or when you're grieving. And I think there's a huge power in making these experiences, putting them on to a map and actually having this as a tool really, to demonstrate people's experiences, but also allowing other people to learn how these systems operate in reality and what might shift To improve them. We've also been doing some work with different systems knowing that I mean, there are different systems in tiny geographical areas that alone across different countries, but we've been exploring that across different countries to understand what do they look like, across Southeast Asia, different countries in Africa. And so we've been getting people to map these again in on big sheets of paper so that people can understand the different relationships, the actors, their components, and then crucially, where would change take place if we wanted to improve experiences. So it's been a really interesting time exploring this kind of hyper locally in one area in St. Christopher's hospice, and that works really just started. So we'll be continuing that throughout the future months, and similarly, developing these similar conversations globally. So we can start looking at what are some of the similarities? And what are some of the differences. But understanding the value of the impact really, of using this new approach, or this new set of principles for leading to change in this area? I think one of the key surprises was how much the concept which is really abstract. We spent a long time working out this idea of complex systems approaches and systems science, and its application to death, dying and grieving. And I wasn't sure how it would be received, how people would make sense of it, and whether it would make sense to people. But what I've been surprised at is how quickly people have said, Oh, yeah, of course that that makes complete sense. That's that's exactly how my experiences have been this that resonates with how I see things. And we hadn't brought this lens in before. And that was what the research was doing kind of from a theoretical perspective. But what's been really surprising is how people have just grasped the concept and said, Absolutely, this really makes sense. Now, how should we use it to shift experiences, and that, for me, is the real value of good research, because it should make sense and make clear something, something that people for some reason hadn't made sense of, and hadn't been clear. And that can be such a valuable tool of just giving someone a new lens, look through a new piece of information, because now people are ready to really run with it. And I thought that process would take much longer, whereas actually, it's been it's been really, really quick. I think one of the things that I am most proud of and can see the value of for in a kind of long term way, is the fact that this isn't kind of complicated, it doesn't need a great deal of tech or a great deal of expertise or knowledge to make this work. And this impact work has really demonstrated that people can take this kind of

new approach that we were, we were writing about in the commission report, people can take it and develop it in their own way, you can really start begin to start seeing the impact really quickly just by people mapping and making explicit the relationships or absence of relationships, and you can just go in there and then begin working on that. So it's, it's a tool, it's got real value, real use. And there are very, very few barriers to using it, it's it can just be often being used. And I see that already, across some of the different groups that we've hosted internationally. And then some of the early work that we're doing in in London. And I think before I started this fellowship, I, we had these ideas that I wasn't sure how they would be picked up and perceived beyond palliative care, because that's where a lot of the discussions around death dying and loss are. It's often palliative care is seen as kind of the holder of all of those issues. And often other other disciplines or other areas don't really see the relevance, it can be harder to convince people of the relevance. Once I got this fellowship from from UCL and gain gave some, again, some really kind of positive feedback from the team there to really say this is relevant, this is important, these questions are important. And you should pursue that. It gave me the confidence and the connections and some of the experience with the different sessions that we'd had really thinking about the different avenues that this work could be taken down. I've applied for another research fellowship within my NHS team that I was successful in achieving and was granted just a couple of months ago. And I would definitely not have put that through or had the kind of depth of understanding of the impact of this work without the impact fellowship. And I'm going to go on to Rice, a much larger research fellowship, Early Career Award over the next month, again, building on a lot of the work, the conversations, the exploration, really the confidence that this fellowship has given me to think this research has real value has real utility. I can now evidence some of that by some of the conversations and the impacts that I'm seeing through this work. And it just gives a kind of weight and an excitement to think actually this this work has a value Beyond palliative care, which is what I've kind of intuitively thought. And now I feel after this year, that's really true. So I can go out to much bigger audiences where this work actually needs to be Saturday. So the St. Christopher's, which is one of the key stakeholders in the UK that we've been working with, through this fellowship, though those relationships are, and this thinking is really, I think just becoming now something that's quite well developed, it's taken a while to get things organised in terms of getting groups together, and working through all the different groups and committees and things to share these ideas. So we've got some plans to work with an artist or designer to capture those maps in a kind of visual way. And that will be over the next month or so. And from then that will really just be the start. Because once those maps are created, there'll be there'll be, I think, really powerful tools to go to commissioners to go to other people named on the map, other components of these death, dying and grieving systems to say, okay, you know, you're actually named in this and that what relationships do you have exist across the system? Where there are no relationships have maybe created? How can we analyse some of these systems to say, these are the barriers or lever leverage points, so that they're kind of the mapping of them is really the first the first part of that whole change process. So I'll be following that up. And that will be something I will remain involved in. And then I'll be applying for some bigger fellowships to really take this work, understanding it in much more detail, looking with working with partners in a CO production way to really understand what this means. And if you use this approach, where could it lead? What kind of bigger impacts could we see? So this is very much the start. And I see this fellowship is giving me the kind of building blocks to go on to the next part to understand first the value of this and really gain that confidence that there's this is a valuable approach and has real potential for change beyond the kind of written paper, the written type on on a on a publication. And, and then the next thing is some of the relationships and understanding of what impact can be some of the talks, we've had been so interesting in terms of lobbying the use of language and museums curating. So it's given me a much broader sense of what this could achieve. And that then, I think that

really comes across when you start writing some of these bigger funding applications. I think if I were to give any advice for people interested in, in developing impact, which really is the fundamental reason as to why we all do research, is that, first of all, just think about it from the beginning, it's not something you add on at the end, it's something that you should really begin working on at the same time as research questions and developing ideas. And that's something I'm definitely going to do in the beginning. So not seeing it as the kind of final phase of dissemination, seeing as integral to your entire project. But I think the thing I feel very strongly about is that impact is not something something that can be delivered by a single person, or even just a single team within one discipline. By its very nature, the complex health challenges that we're all trying to address, need multiple different perspectives. So we also, as researchers in one area, don't really fully understand the implications of research in other allied but linked areas. So we need to make those relationships again, early on at the beginning, not right at the end, just during that kind of end of the research. We need to be making those relationships early on, saying what would this what impact would this have for your discipline, and then crucially, going beyond just academic disciplines, to public partners, which has been a really important part of learning about those broader partners within the fellowship. So make those relationships early. Because you don't know that impact and you don't know those, those connections really till you make them. And that's where I think I've learned a lot of the value. And that's what's really fun learning things that you would not have been able to do, or you would not have known about just by yourself or just within your own department. So I think, kind of lift your head up. Think creatively, broadly and confidently just get in contact with people because actually people are really interested to hear of links in kind of linked but slightly different disciplines. And that's where I think the real kind of energy and excitement comes from