Scholl Academic Centre, Hospice Isle of Man, Fourth Annual Research Symposium
Questions and Answers

Kenny Steele, CEO Highland Hospice

Q: “You didn’t have a detailed plan at the start, this is very much bottom-up emergent work… What would you say was your compass or your ‘why’? Can you encapsulate that? What was your vision for your collaboration?”
A: “It’s being coming for a long time, this collaboration. I always thought it was too difficult. I suppose it’s one of the silver linings of the pandemic, where we recognised that the whole health and social care system was getting turned on its head and it was facing a period of crisis. Periods of crisis are an excellent time to put in change. One thing I did not mention, and it is quite an important aspect, is we have developed a 1.5 million transformation fund for End of Life Care Together (EOLCT). I don’t want to focus on that fund because I want to focus on the network but the money helps. The money makes people think, ‘aha, you are actually serious about this’. Now I had a real battle with my board not to set targets and I say there’s not a plan, there is a plan. Our plan is to increase identification, so with our primary care working group doing that. We have a digital working group, we have all these working groups, and each of those working groups has plans, but it’s up to those working groups to create the plans. My job is to provide the vision, I’m very clear about the vision; we’re going to deliver those outcomes and we’re going to measure those outcomes. I know we’re going to fail on those outcomes, but we all know what those outcomes are that are important to people at end of life – we’ve had loads of research on that, but who measures it? I’m not seeing anybody really properly measuring that, so we’re actually investing quite a lot in the measurement piece because that’s critical. I don’t know how to fix this, I’ve been in this for 11 years, and I still don’t know how to fix it, nobody knows how to fix it, it’s too complex. You’ve got to create a learning system and it is basic improvement science. That’s the target, it’s to create an improvement science methodology whilst improving the things that we think need to improve. That might change as we go forward.”

Q: Do you have a standardised template for care plans? If so, could I please see a copy?
A: We are working on a standardised anticipatory care plan, with ReSPECT form being the foundation.

Q: With all the different organisations involved in this, how do you envisage which organisation wound coordinate and the responsibility of costs?
A: “It was interesting hearing earlier on about your Oversight Group. We have an oversight group of about 20 people on it from a whole range of organisations. We talk about them being a population stewardship forum. Their responsibility is to the population. There’s 1.5 million as a transformation fund and I’m very clear, that 1.5 million is our population’s 1.5 million. Most of that money has actually come from the hospice and there has to be some say, from my board, to a certain extent, on how that money is spent but the way I justify it is through the oversight group and utilising that to guide where the money is spent. If there’s a single budget holder, then you have a hierarchy, this cannot be hierarchical. If this is all about the hospice and I’m just getting partners around me to make me look good, this is not going to work. There’s got to be clarity of joint responsibility. Through that, I’m starting to eke money out of the statutory health and social care system as well. It is complex but I think for the partnership to work well, it’s got to be a joint responsibility”

Q: Have you identified any model "annual reports" that have helped clarify what is best practice and how they can be improved?
A: “We’re working with 3D consultancy which is headed up by Professor Muir Gray. They have developed a template which they actually used in North East Essex. North East Essex is the only place I have seen which has had at least an attempt at an annual report. They produce what they call an ‘Accounting for Value’ report for end of life care. It’s an attempt to look at all the money that is spent in this arena and look at ‘is this being spent in the way that our population would want us to spend the money?’ And actually being quite brutally honest around that. I think that there are templates but it is very early days. I’m not saying that our annual report is going to be perfect the first time that we produce it. In fact, I know it’s not going to be. The important thing is that we do produce it.”

Q: In my role I as mental health nurse I cover hospital liaison at times. I work with over 65 population and a large portion has a dementia diagnosis. I feel we missing end of life training, at times we come across management complexity towards end of life and in addition delirium. Do you integrate mental health into the end of life care development? Can you point out if there is specific research regarding dementia patient end of life care and perhaps care plans.
A: Every death with a care need towards the end of life comes under the remit of EOLCT. Dementia is the fastest growing care need towards the end of life and needs to be identified as such- care homes/nursing homes/ care at home needs to come under the umbrella of EOLCT.

Dr Emily Collis, Consultant in Palliative Medicine, Central North West London NHS Foundation Trust

Q: “You said you started this during Covid, so it was remote from the outset. How would you design an ideal induction period to build the relationships with the local team before you start the service? What would you do?”
A: “That’s a very good question. In reality, of all the hospices I’ve been involved in for remote support, because I’ve dropped in and out of other hospices when they’ve had short periods of need, it literally has been like a remote meeting to discuss what the role needs to be, and possibly two remote meetings over a very short time period, because often the need is identified and needs to be filled as soon as possible or the day before. Then we go straight into it. I think actually, I feel like that works because in a way it’s by doing that you learn the culture. I’m very much one for the apprenticeship model of learning and the concept of legitimate peripheral participation, where you start on the fringes and then you work your way more core. I feel like if you’re not actually doing something then it’s very hard to truly have that learning and that incorporation into the culture. I feel that sometimes, in our induction periods, we’re a bit artificial and sometimes not that useful so I think actually just starting and really thinking carefully about what the need may be and making the best plan possible. Taking our knowledge of different services and what has worked in different places and the local knowledge of what the situation is and what the actual local need is, try to make the best fit plan. Draw up a plan A, start with it, I wouldn’t delay it because of the induction. Make sure that in that initial phase you’ve got a review period where you can review weekly or second weekly. I think that flexibility is really important.”

Q: I work within the community nursing team on the Isle of Man who work with end of life at home, how much input do you have with these patients or is it more in-patient driven?

A: “Good question. What we do is we discuss all the patients on the in-patient unit. If it’s very straight forward, that might be quite brief. If it’s more complex, that’s more in-depth. When we go through the multidisciplinary team (MDT) in the morning, we highlight if there are any patients who are on the hospice at home or on the community team books for discussion that can be brought to the ward round. I suspect that that opportunity isn’t used as much as it could be, I think the team would agree with me in saying. It is very much there for that. If community clinical nurse specialists (CNSs) want to bring more patients to the meeting, that’s absolutely fine. I think we would always be able to make time for that.”

Dr Seamus Coyle, Consultant in Palliative Medicine, Clatterbridge Cancer Centre MHS Foundation Trust

Q: Changes in mitochondrial membrane are known to be a very early indication of programme cell death - is that part of your risk model or do you think that your active metabolites can trigger that process?
A: “That’s a good question. The thing is, we don’t know yet. This is just an analysis of all we found and you go ‘alright, here are the different clues of what we think is going to go on’. Now it’s about going to get some blood samples from patients and then actually look at the mitochondria themselves. I’m uncertain if it would cause apoptosis in the cells because I’m not sure if we got massive apoptosis in the bodies. Do our cells start dying off by apoptosis and that’s how you get chronic necrosis? Nobody knows. That’s an interesting suggestion. One of the things we will start to do is look at the mitochondria themselves and what they’re producing. I’m not 100% sure, how do you detect apoptosis within the body when the body absorbs all the apoptosised bodies?”

Professor George Crooks, CEO, Digital Health & Care Innovation Centre, Scotland

Q: “Earlier on you said about shifting resources around prevention and detection. It leads you think that investing in public health would be a good idea yet what we’ve seen over the past decade or two is a disinvestment in public health. I think that’s sometimes because of the political cycles that we live in. The things you do for prevention now that has an impact 10 or 20 years later doesn’t give the payback to our political leaders. I wondered how we can work with that and affect that into the future and what your thoughts are on that?”
A: “You’re absolutely right, it’s been a kind of Cinderella. I think we’ve got a great opportunity because clearly Covid demonstrated that every public health system around the world has suffered from lack of investment. All our health protection services were either been conducted and delivered by pieces of paper and a pen or on an Excel spreadsheet and that was the strength and breadth of it. There is now a recognition that there has to be a significant public health investment, but for us, it’s all about data and it’s about trend data. We talk about population health now and that is now an unstoppable force because government recognises that it needs to risk stratify its population because it doesn’t have enough resource to spread it across the whole of the community. So how do you risk stratify your population? You do that with data and collecting relevant data. I think there are opportunities today that we didn’t have two, three or five years ago. I can see that if we as clinical communities can get ourselves mobilised to have these constructive conversations

about where the real value add would be from bringing these solutions to bear, we've got a chance of moving the dial a little bit more in one direction."

Q: How do you balance the need to balance data at a population level and data at a personal level?
A: "That's a very interesting one and my view is that we actually need to focus on it at the personal level. First of all, there's this point about we need to collect the data once and we need to collect the data at the point of delivery. We're not good at that at the moment. We don't have standard datasets. Also, we lock data away in silos. We need to stop doing that. So we need to actually collect our data in one way and this whole thing about Standards and Interoperability is fundamental here. Then you can scale that data up in all sorts of ways. Data no longer has to move from where it's held. We've got technologies that can interrogate it safely, effectively and securely without the data having to move. I would focus on the citizen because personalisation is fundamentally important. The global technology companies learned this a number of years ago, Amazon, for example, Google. They use it to lock us in as customers and exploit that data unashamedly. If we take their technologies but use it ethically, that would make life much, much easier, because personalisation is the key to the future."

Q: I appreciate and agree regarding ownership of personal data to the individual in care (the patient) and I daily face disappointment of patient and carers having to repeat the story over and over again. I believe there is a mistrust in sharing of assessments and in the professional whom assess; as well a misuse/misinterpretation of GDPR that indicate a gap in knowledge especially in health care fields. How do you think we can overcome this barriers? Any suggestion on how to develop inter disciplinary trust. Do you think individuals are ready to ownership their data?
A: I firmly believe individuals are well equipped to have ownership of their own data, after all it is their information and life stories! On a practical level, this means that they have full control over data sharing and in a consent driven environment that is GDPR compliant they can share their data with whomever they believe will act in their best interests, including family, friends, voluntary sector and others etc. I do not suggest for one minute we are looking to turn everyone into mini data scientists, this would be ridiculous but citizens having the ability to access, correct share and if appropriate curate their own data will deliver many more advantages than disadvantages. As you say, TRUST is key to all of this particularly in health care provision so designing systems that benefit the patient, their family and those delivering health care in equal measure is key. Being able to demonstrate the art of the possible through simulations and demonstrations can prompt discussions and create greater understanding and can de risk the innovation process. This is the DHI Exchange model that my organisation uses regularly and with increasingly positive results in securing adoption and scaling of new digital supported services.

Professor Max Watson, Director of Project ECHO, Hospice UK

Q: Any advice, Max, to influence our Manx Care Colleagues to embrace ECHO more. We currently have ECHO for nursing homes, residential homes, pharmacy and Ward sisters / DN team leads?
A: "I think you have done a superb job on the Island in using ECHO and bringing ECHO to the Island. You have modelled it and you have shown it. I think there's been quite a bit of turmoil in the Isle of Man health system. You can do a lot of work with one personality and you're getting somewhere, and then suddenly there's someone else in post. We've been very fortunate in Northern Ireland in one respect and in another way not so. We have a health service which is in need of transformation,

we had the worst out-patient figures before Covid and they have continued to deteriorate. We also have a health service which is desperate to find solutions and to build different ways of working. Maybe that desperation was one of the reasons why seeing what had been achieved in ECHO in other parts of the world, made them particularly willing to trust and to give ECHO a go. I think the key experience is to have commissioners attend ECHO sessions and to see the value, not just in transmitting information but also hearing information. Commissioners participating in ECHO really benefit from finding out from the coal face what is actually happening but also then to be able to develop new ways of innovation. My encouragement would be to keep on, you're doing a brilliant job, and to encourage people, encourage many of the key influencers to attend ECHO sessions to be infected."

Q: "A question about patient outcomes because one of the things we're good at is showing how maybe the processes and how we evaluate healthcare professionals, but it's always the Holy Grail to measure the patient outcomes and impact on those. You mentioned that 15% demonstrated that, what kind of measures were in place to capture that?"
A: "Each network is different. But as one example consider the optometry ECHO. The eye system in Northern Ireland is all centralised in one hospital so referrals in for follow-up are on one database. So you are able to see where people have come from and to see the impact of an intervention. When we introduced ECHO, we introduced ECHO across a range of optometrists and then we were able to compare the referral rates and the impacts of patients who had been seen by the ECHO-supported optometrist in comparison with those optometrists who didn't have ECHO support. You could see very clearly the referral rate changed and that when we went out and spoke to patients about their experience, we were able to link that up, and patients really appreciated not having to travel into Belfast to get good quality, ongoing care for their glaucoma. It wasn't our database that provided the concrete data, but there was one there and we were able to use to see the impact of ECHO on referrals".

Dr Amara Nwosu, Senior Clinical Lecturer in Palliative Care, Lancaster Medical School, Lancaster University

Q: "I think that the pandemic has in some ways thrust the use of digital technologies, accelerated some and probably hampered others. What do you think is the legacy that we've got to learn from after Covid and how will it change palliative care moving forward?"
A: I think how organisations cope with change is important. For example, in the Royal Liverpool Hospital we made the change from paper notes to electronic notes; this was a change that we needed to make. Staff got on with it and there were many positives from it. I think the same is true with the digital health; investing in collaboration and participating in events like this are good. However, many of the technologies we are using haven't been designed specifically for use with our palliative patient group. For example, to go back to my earlier example, I believe that using iPads in palliative care to conduct patient and family meetings is a positive thing. However, I think if we were going to plan it out again, we would have probably would had developed a distress protocol to guide staff to support patients and caregivers if they became distressed when they during, or at the end of, the call. I think it's important about how we use these technologies safely and that safety is very much the human part of it. The technologies are here now so I think the legacy is that we're going to be using these technologies for a while, however, we need to be aware that many of the innovations that we've talked about (artificial intelligence, big data, wearable technology) were not designed

with the specific needs of our patient group in mind. I believe that palliative care patients have different needs compared to many general medical and surgical patients, because of their morbidity and the mortality. We can’t just assume that just because it’s working well in oncology or geriatrics that our patients are going to be able to use it. For example, I think many assume that smart home technology and assistive technologies will just ‘work’ with our patients; however, I think it’s potentially a dangerous assumption as we could have unintended consequences. Even though the intention may be good, there is a risk that they could actually cause harm for some people.