**International transfer and translation of an end of life care intervention: the case of the Liverpool Care Pathway for the dying patient**

**Extended data based on analysis of interviews**

Jane Seymour, David Clark, Hamilton Inbadas

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**Purpose**

The Liverpool Care Pathway (LCP) showed great potential when first developed in the United Kingdom (UK) from the late 1990s (Ellershaw & Wilkinson, 2011), and led to further interest and implementation in over 20 other countries.

This document represents the underlying data analysis for a study in which David Clark, Hamilton Inbadas and Jane Seymour examine how the Liverpool Care Pathway (LCP) for the dying patient was transferred to countries beyond the UK, by which actors, and with what consequences for policy and practice. In that analysis we investigate the processes whereby the LCP was adopted in other countries around the world, examine the evidence for effectiveness that was accumulated in research studies of the LCP when implemented internationally and explain the international consequences of its discontinuation in the UK from 2014, in particular for those countries that had adopted it at scale.The full analysis synthesises findings from 95 papers contained in a historical narrative literature review on the implementation of the LCP outside the United Kingdom, alongside data from 18 qualitative interviews with 19 key actors involved. Our qualitative analysis of these interviews is presented here, as extended data to the main publication.

NB: The full transcripts ‘raw’ transcripts have not been provided as extended data, in deference to the interviewees; but the version provided here has been checked by all interviewees, thereby ensuring that it reflects the interviews that took place the views of the individuals concerned. This document should be read in conjunction with: *International transfer and translation of an end of life care intervention: the case of the Liverpool Care Pathway for the dying patient* by David Clark, Hamilton Inbadas and Jane Seymour.

**Methods for the interview study**

*Sampling*

Purposive and snowballing sampling techniques were used to identify potential participants for qualitative semi-structured interviews about the international spread of the LCP. This approach to sampling facilitates the choice of respondents who are strategically located in a situation from where they are able to shed light on the subject of study at hand (Gerson & Horowitz, 2002; Ritchie, Lewis, Nicholls, & Ormston, 2013). The target group included: clinicians in leading roles with experience of LCP implementation, researchers who had studied the LCP outside of the UK, policy makers involved in LCP introduction, and global experts in palliative care with knowledge of LCP introduction in particular non-UK settings.

The initial sampling frame consisted of those individuals reporting on the use of the LCP in the 2011 LCP handbook (Smeding, Bolger and Ellershaw 2011), totalling 11 countries (Argentina; Slovenia; India; Norway; Italy; Switzerland, Germany and Austria (the so-called ‘DACH’ German speaking collaborative); Sweden; Netherlands; New Zealand). Everyone we approached agreed to take part, with the exception of the person from Slovenia. Following leads from the linked literature review and recommendations from interviewees, we then invited potential interviewees from seven further countries where there was evidence of LCP implementation; people from four countries accepted (Australia, Belgium, Denmark and Japan), whilst three (from Hong Kong, Ireland and Spain) declined to take part. In two instances (New Zealand, Belgium) two people took part in the same interview. For some countries we had interviews with more than one person. In two countries we interviewed two separate individuals (Australia, Japan) in one country we interviewed the same person twice (Netherlands). We thereby completed 19 interviews with 20 people from 14 countries in total. The interviews took place between August 2017 and December 2019.

*Recruitment*

We sent introductory emails to potential interviewees, explaining the purpose of the study and enclosing an information sheet. Individuals were invited to a telephone or SKYPE interview at a mutually convenient time. We asked individuals to consider participating in an ‘on the record’ interview (although this was not mandatory), since interviewees were likely to be easily identified by colleagues in the palliative care field from our resulting reports and publications. Individuals who agreed to take part in an interview were asked to complete a consent form, and to indicate on the latter whether they were willing to participate ‘on the record’. All of them agreed to this. Likewise, all interviewees (with one exception, who withdrew from the study at this stage) have checked and verified this ‘extended data’ document, in some cases making minor amendments to their quoted comments, and have given their approval for: 1) some parts of this document being used in the published paper, 2) being identifiable within it, and 3) to the ‘extended data’ being made available with the published paper. The analysis presented here is therefore based on 18 interviews with 19 people from 14 countries.

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*Conduct and analysis of the interviews*

We developed an *aide memoire* (see Figure 1) based on the aims of our project and themes in the literature review. Interviews were audio recorded and transcribed by a specialist agency, bound by a confidentiality clause. The *aide memoire* was adapted according to the context of the interview and the background of the interviewee. Where appropriate, we sometimes included more than one person in the interview. In one case (the Netherlands), we carried out a repeat interview to clarify material and to bring our understanding of research developments up to date. In another case (Belgium) the interview was conducted in two parts because of technical challenges and poor sound quality in the first part of the interview. Interviews ranged in length from 36 to 66 minutes. All three authors were involved with the interviews (Inbadas, 12 Seymour, 5 Clark, 2).

Our analysis followed the principles of the framework approach to qualitative data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Framework analysis sits within the broad range of thematic approaches to qualitative analysis and is especially appropriate where interviews have followed a similar structure or line of discussion. Its key feature involves the development of matrices to enable systematic comparison of content between ‘cases’ or interviews (sometimes called ‘charting’). It can complement the use of other more analytical strategies: for example, in this study we also undertook a preliminary coding exercise using NVIVO and, as a step towards interpretation, subsequently developed a detailed narrative ‘write up’ for each interview.

**Figure 1: Interview *aide memoire***

1. Describe how the LCP came to your country:
   1. Where did you (or whoever introduced it in your country) first came across LCP?
   2. Why did you think it was a good idea to use LCP in your country?
   3. Year of implementation of LCP in your country?
   4. At what level is the LCP implemented – local, regional or national?
   5. Is LCP recognised in health policy or used in individual hospitals?
2. What were the opportunities and challenges in your country to implement LCP?
3. What adaptations were made to the LCP to suit your country?
   1. How was the need for adaptation recognised?
   2. What was the role of the LCP leads in the UK in its adaptation in your country?
4. Were there issues araising from the differences in health care systems, culture and societal attitudes that influenced the implementation of the LCP and how did you deal with these?
5. Was the implementation of LCP supported by the government and was it adequately funded? In what ways?
6. The ‘Neuberger’ Review in the UK highlighted a number of issues that led to LCP's withdrawal in the UK- did these cause any concerns in your country?
   1. Use of terminology such as: 'pathway', 'dying patient', etc
   2. No substantial evidence of effectiveness of LCP
   3. Senior responsible clinician was not always involved in deciding to put someone on LCP; issues around training
   4. Involvement of / communication with family members
   5. Issues with hydration, nutrition and sedation
7. Has there been any impact of the withdrawal of LCP in the UK in your country?
   1. What was your reaction?
   2. What do you think about the report?
   3. Any change made/considered to LCP in your country?
8. Research evidence of the use of LCP in your country?
9. Documents, reviews, surveys and service evaluation available? Could you please send copies?

**Findings**

Table 1 lists the 19 interviews we conducted with 20 people from 14 countries. Six countries with some measure of LCP activity identified in the literature review were therefore not included in the interviews (Spain, Ireland, China, Slovenia, Singapore, Hong Kong). All interviewees agreed to be interviewed ‘on the record’ and are thereby identifiable in our reporting. All interviewees gave their consent for this underlying data document to be placed in the public domain. One interviewee withdrew from the project at the time of consultation on the document.

**Table 2: Interviewees by country**

|  |  |  |
| --- | --- | --- |
| **Country** | **Respondents’ names and roles** | **Interview number** |
| India (1 interview) | Dr Stanley C. Macaden, Palliative Care Consultant Physician, Bangalore Baptist Hospital and Christian Medical Association of India (CMAI) | 1 |
| New Zealand (1 interview with two people) | Dr Simon G. Allan, Consultant Medical Oncologist and Palliative Care Physician and Bridget Marshall, Clinical Nurse Specialist and National LCP Lead | 2 |
| Argentina (2 interviews) | Dr Vilma Tripodoro, Chair Palliative Care Department, Lanari Institute of Medical Research, Buenos Aires | 3 |
|  | Dr Gustavo De Simone, Director Pallium Latinoamérica | 6 |
| Germany (1 interview) | Professor Raymond Voltz, Director of the Center of Palliative Medicine, University Hospital Cologne | 4 |
| Norway (1 interview) | Professor Dagny Faksvåg Haugen, Professor of Palliative Medicine, University of Bergen | 5 |
| Sweden (1 interview) | Professor Carl Johan Fürst, Professor of [Oncology and Pathology,](https://www.lunduniversity.lu.se/lucat/group/v1000472) Lund University | 7 |
| Australia (2 interviews) | Associate Professor Dr Carol Douglas, School of Clinical Medicine, University of Queensland and Director of Palliative and Supportive Care Service, Royal Brisbane and Women’s Hospital. | 8 |
|  | Dr Mark Boughey, Deputy Director, St Vincent’s Hospital Melbourne, Centre for Palliative Care, Associate Professor, The University of Melbourne | 12 |
| Netherlands (2 interviews with the same person) | Dr Lia van Zuylen, Consultant Medical Oncologist, Department of Medical Oncology, Erasmus MC Cancer Institute, Rotterdam (From January 2020 Medical Oncologist and Professor of Clinical Palliative Care, Department of Medical Oncology, Amsterdam UMC. | 9 and 14 |
| Japan (2 interviews) | Professor Mitsunori Miyashita, Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, Sendai. | 10 |
|  | Dr Ai Oishi, PhD student, Primary Palliative Care Research Group, Centre for Population Health Sciences, Medical School, University of Edinburgh, and GP trained in Japan | 11 |
| Belgium (1 interview with two people) | Dr Tinne Smets, senior researcher, Vrije Universiteit Brussel (VUB) & Ghent University End-of-Life Care research group and Dr Kim Beernaert, FWO post-doctoral fellow at Ghent University and chair of the “Palliative care for people with cancer” Research Programme at the End-of-Life Care Research Group of the Vrije Universiteit Brussel (VUB) & Ghent University | 15 |
| Denmark (1 interview) | Dr Svend Saalbach Ottesen, medical oncologist and a specialist in palliative medicine, Roskilde, Eastern Denmark | 16 |
| Switzerland (1 interview) | Professor Steffen Eychmüller, Institute of Social and Preventive Medicine, University of Bern, Switzerland. | 17 |
| Austria (1 interview) | Dr Elisabeth Medicus, retired palliative medicine physician. | 18 |
| Italy (1 interview) | Dr Massimo Costantini, Azienda USL-IRCCS of Reggio Emilia, Italy | 19 |
| Confidential | Interviewee withdrew from study | 13 |

**1. Primary rationales and motivations for use of the LCP**

Interviewees reported an overlapping range of motivations and rationales for introducing the LCP into their own countries.

***A structured way to improve the care of the dying***

All interviewees reported that an important motivation for using the LCP was the opportunity it presented to improve the care of the dying, although the care setting they targeted varied. Some focused primarily on a specialist palliative care context (such as an inpatient unit or hospice) and others on a general palliative care context (such as hospital wards or care homes); a minority emphasised the importance of the relationship between specialist palliative care teams and general health care teams when using the LCP. We expand on this below, when looking at interviewees’ use of the LCP. Regardless of care context and target, many interviewees referred to the value they perceived of the structured and systematic approach to the care of the dying that the LCP encouraged. For example, in Norway, Professor Dagny Faksvåg Haugen (LCP 5) recalled the potential of the LCP as a structured means to optimise care of the dying and make quality of care less dependent on the individual practices of clinicians:

*There was really nothing new in the LCP. But it structured what we already did or wanted to do in a very good way. We saw it as a good checklist and a framework securing a certain quality of care ... no aspect was forgotten. So we thought that providing this framework for clinical decision-making provided a standard for good care. So it would be more uniform everywhere, not so much dependent on the individual professional* (Professor Dagny Faksvåg Haugen, LCP 5, Norway).

*Reputation of the LCP or networks with the LCP group in the UK*

Interviewees from 10 countries recalled that their networks with the LCP team in the UK or the reputation of the latter, especially via the publications associated with the LCP, were primary motivators. Some relationships between our interviewees and the UK LCP team went back over many years. For example, In Sweden, Professor Carl Johan Fürst recalled his introduction to the LCP was through personal contact with John Ellershaw: *‘…hearing about it from the source itself, the first time’* (LCP 7). A similarly long standing relationship was reported in the Netherlands by Dr Lia van Zuylen, who worked at that time in the Erasmus MC Cancer Institute in Rotterdam, where John Ellershaw had a visiting position (LCP 9 and LCP 14). In the three German speaking countries (Germany, Austria, Switzerland) a collaborative known as ‘DACH’ was founded on long standing professional ties that had existed since the 1990s between the Liverpool team and a clinical leader working in Switzerland, Professor Steffen Eychmüller:

*How [the] LCP came to Germany… It was through connections with the Liverpool Group and in person I think it was mainly for the German speaking countries, it was Steffen Eychmüller who has the longest standing contact with the Liverpool group. And through him we got interested in that* (Professor Raymond Voltz, Germany, LCP 4).

*I thought about it now and I think it was at the EAPC Congress in Aachen in 2005. There, maybe, I heard Steffen Eychmüller or there was a poster … I felt that this was a good approach to the care of the dying patients* (Dr Elisabeth Medicus, LCP 18, Austria).

Others reported more recent involvement: some were founding participants in an international LCP interest group that took opportunities to meet at annual conferences of the European Association for Palliative Care and which, in 2008, broadened into a formal collaborative of nine countries known as ‘OPCARE 9’ funded by the EU. This enabled their participation in dedicated international meetings and in some contexts provided resources for expenses associated with translation of the LCP documentation:

*I had seen publications on LCP and it was probably commensurate with the year the textbook on the LCP was published that there was ... I think it was the third or maybe second meeting of an international group on LCP that John Ellershaw was holding. It was in London. For whatever reason I probably was in touch with John Ellershaw and made that meeting and at that point New Zealand was part of a ... I don't know, a six-nation, five/six-nation interest group that formed the basis of the international collaborative subsequently. So I suppose we were in on the early days of international interest and that’s really where it sprang from. I came back to find that members of my team had already been interested in reading round the LCP and we formed a sort of interest group within Arohanui Hospice. I suppose that formed the nexus of a national interest that focused on our hospice here in Palmerston North* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand).

*Well, we met with the Liverpool Institute and John Ellershaw's group in 2008, because of that participation in OPCARE9. You know the international research group? Argentina was one of the countries participating in the project, with another eight countries, and we met the group in this occasion. So, since 2008 we start working on the best care of the dying, in this research group* (Dr Vilma Tripodoro, LCP 3, Argentina)

Interviewees from Australia, Norway and Denmark reported less immediate personal familiarity with the LCP and the UK team. Their motivations to use the LCP followed interactions with colleagues who knew about the LCP, their own visits to the UK, or becoming aware of the LCP at international conferences.

In Queensland, Australia, the genesis of the LCP introduction was described by Associate Professor Carol Douglas (LCP 8) as a study in the Royal Brisbane hospital, where she was appointed Director of Palliative care in 2006/6 and asked by the head of the hospital *‘to do something about the very poor state of dying in this facility’*. She was subsequently approached by a senior clinical colleague (who had worked in London) to collaborate on a study mapping the last 24-48 hours of life of patients; this led to an adaptation of the LCP:

*From that, I think that’s what first triggered my interest in having a framework to support junior medical staff and nurses. I was successful in getting some Commonwealth funding in about 2007, to try and develop a pathway for dying.* (Associate Professor Carol Douglas, LCP 8, Queensland, Australia)

Similarly, in Norway, Professor Dagny Faksvåg Haugen (LCP 5) reported how the LCP came to her attention from networking with a colleague who had been introduced to the LCP during studies for a post graduate degree. This colleague subsequently presented his work at a medical meeting:

*One quite well-known palliative care doctor in Norway, he used to work in the northern part, and he was doing a master's study in public health. And then he discovered the book, Care of the Dying, a Pathway to Excellence. So he wanted to do something for his master's project based on that book. And when he later came back to work, he changed jobs and he was going to establish a palliative care unit in a nursing home, and from what he had read about the LCP he wanted to use this as a tool in his newly established unit. So that was the first place in Norway and that was around 2003, 2004. And at this unit they had the first experiences and he presented these experiences at the annual meeting of the Norwegian Association for Palliative Medicine, [a] small organisation for palliative medicine physicians. And that was in 2005* (Professor Dagny Faksvåg Haugen, LCP 5, Norway)

Dr Svend Saalbach Ottesen, an oncologist who had led a palliative care unit in Denmark between 2004 and 2015 (LCP 16), recalled that his introduction to the LCP came through a specialist course in palliative care for the Nordic countries and then the opportunity to attend a course in Liverpool on the LCP in 2007:

*I think 2004 they established the Nordic Specialist course you probably heard about … I was so fortunate that I was on the first course, and obtained the specialist [training] in palliative care. In our oncology department we introduced a palliative care unit in I think it was six beds. And it was working from 2004 to 2015 … And in that setting we had the palliative care unit. We started at the basic level, and in 11 years in the specialist care setting. It was in that setting we got our eyes on the Liverpool Care Pathway. In fact, in 2007 I think we were in Liverpool on a training course for the Liverpool Care Pathway, three nurses and myself* (Dr Svend Saalbach Ottesen, LCP 16, Denmark)

*A research rationale*

In some cases, notably Italy, Belgium, Switzerland, the Netherlands and Japan, interviewees reported a research oriented rationale to the introduction and assessment of the LCP.

In Italy, Dr Costantini (LCP 19) recalled first hearing about the LCP in around 2008 / 2009 at the same time as an opportunity presented itself to apply for research funding from the Italian Ministry of Health. He decided to join the LCP international reference group with the intent to immediately embark on a research study of the LCP:

…*when I heard about LCP, to be honest I can’t remember who spoke to me about that, I looked* *for* *that on the web and I found the Liverpool group. I asked for information and they replied giving me information about that and saying that they didn’t have any reference person in Italy. I had to decide what to do, so my decision to join the international group was a consequence of my decision to start with a research trajectory in Italy because it was really clear to me that LCP had to be assessed before implemented. The evidence in my opinion was not strong enough to justify implementation without research. In the meantime, I joined the international group and I started the process for research in Italy* (Dr Massimo Costantini, LCP 19, Italy)

Interviewees from Belgium (LCP 15), whose primary roles were as University based palliative care researchers rather than clinicians, also reported a primarily research oriented rationale to introducing the LCP. They reported little or no previous familiarity with the key players in the UK team, but good contacts with key researchers in Europe (in Italy and in the Netherlands) who were engaged in some of the first quasi experimental and RCT studies of the LCP. In 2011, opportunities for palliative care research funding via the Flemish Government Agency for Innovation by Science and Technology resulted in resources for six palliative care studies. A cluster-randomised trial of an adapted version of the LCP (called the CAREful intervention) was one of these. It focused on whether the adapted version of the LCP improved levels of comfort at the end of life among patients in geriatric wards in ten hospitals in Flanders:

*So, it started [as a] research idea back in 2011 and it was (name) who wrote a research proposal focused on acute geriatric ward for older people. I’m not sure why she focused on this particular setting, but the idea was that there was some evidence that it was effective in cancer patients but not in patients dying from other conditions and especially not in older patients so I think they saw an opportunity to test it in this population and setting and so in 2011 we started with this … So we started by talking to people in the Netherlands and also to Dr Costantini in Italy, we knew he was doing a big trial in hospital with cancer patients, so we went to Italy to talk to him and we went to the Netherlands to talk to those people and we also went to Professor Ellershaw’s group in the UK and we started with the various documents and the program and thought, well, what can we use, what is suitable, do we need to adapt this and how can we make this work in Belgium* (Dr Tinne Smets and Dr Kim Beernaert, LCP 15, Belgium)

A strong research focus and rationale was also discernible in the accounts of Dr Lia van Zuylen from the Netherlands (LCP 9 and 14) and Professor Steffen Eychmüller (LCP 17) from Switzerland, in both cases building on their personal knowledge of Professor Ellershaw and his work:

*I used to work in St. Gallen in the beginning and we decided to become like a collaborative centre for the German speaking regions. We translated everything, the whole document and we also established the training programme in German for health professionals. We had also, in early 2003 I think we started, we got the opportunity to establish in the whole hospital a programme for quality improvement and one of the seven standards became care for the dying. So this was, for us, something like a lap to establish and to test the dissemination programme within a tertiary hospital*. (Professor Steffen Eychmüller, LCP 17, Switzerland)

*We translated it by EORTC guidelines for forward/backward translation and after the translation period we introduced it in three settings. In our own palliative care unit, in Erasmus MC, in a nursing home and in a hospice.*

*I: And that was all … was that all in one region? Or was it a local area?*

*The Erasmus MC and nursing home were in Rotterdam and the other – the hospice – was close by Rotterdam. So that was just to give it a try, do we like to work with it? And it showed … we liked to work with it and then I have some moments I remember very well. I remember very well my first talk with John about this LCP. And I remember also very well that I went to the Head of our Department and that I had a discussion that we would like to work with this document … But he said, we don’t know if patients have benefit from it. In the UK there was already a big rush around implementation. But there was no scientific evidence of benefit. So the Head said, if you want to introduce this it will take time and energy. You have to know if it gives benefits for the patients. So that was the moment that I said, okay, now I have to do something else, I have to go into research and I was thinking about it because I was not familiar with this kind of research* (Dr Lia van Zuylen, LCP 14, Netherlands)

Dr van Zuylen went on to have a close collaboration with Professor Agnes van der Heide, a leading researcher in palliative care and research relating to care and decisions around the end of life specifically.

In Japan, Professor Mitsunori Miyashita (LCP 10), a Professor of Palliative Care Nursing, described how his initial introduction to the LCP was related to his knowledge of an early attempt to implement it by a medical doctor, which had started in 2004. The attempt failed for two reasons: scale of the task and the difficulty associated with translation into the Japanese clinical context. This highlighted the importance of preliminary research testing. Professor Miyashita describes how he assumed the role of principal investigator of pilot studies in two in patient palliative care units in 2008/9:

*I had known the project to start. But I was not a member… I was not in the membership of the LCP [group] at the starting point. At first, Dr (name) was principal investigator. Then he discussed with the LCP Central team [in the] UK and proceeded to translate. But this project was …[did] not work well. The implementation was delayed because … one reason is … he’s a clinical doctor. He was so busy. The second reason is I'd say, it was difficult to agree with translation especially on this algorithm… [and]…the usage of medicine…the progression was very slow. Then I entered the team. And I became principal investigator … I joined into this team in 2008 or 2009. Then I completed the translation and pilot… [and] did pilot tests at two inpatient palliative care units* (Professor Mitsunori Miyashita, LCP 10, Japan)

***Translating and adapting the LCP prior to use***

In 11 countries the LCP required translation and a variable degree of cultural or contextual adaptation. In the other three countries (New Zealand, Australia and India), there was no need for translation but some adaptations were necessary. For example, in India adaptation was necessary for use in home care contexts.

Interviewees gave variable accounts of their recollection of the translation and adaptation process. Their emphasis varied from a focus on precise and exact translation of the UK documents (often referring to the use of translation guidelines published by the European Organisation for Research and Treatment of Cancer)[[1]](#footnote-1) as well as to the use of the LCP as a framework or set of principles for care of the dying. For example, Dr Mark Boughey talked about the process of slightly adapting the LCP to fit with the Victorian State context in Australia, but at the same time trying to ensure congruence with the ten key principles of the LCP promoted by the Liverpool innovators (LCP 12):

*So, Liverpool … so the Marie Curie Institute said, “Look, please use what we’re doing, but you need to develop a document that adheres to the 10 core principles and shows therefore, what the best (unclear) pathways methodology.” So, basically, a document of their (unclear) and processes, but maintains some for the language that was pertinent to the Australian environment* (Dr Mark Boughey, LCP 12, Victoria, Australia)

In Norway, Professor Dagny Faksvåg Haugen (LCP 5) recalled how a *‘formal translation was made based on EORTC principles’* of version 11 of the LCP and that initially: ‘…*we really made very few changes’,* with version 11 subsequently used in a range of care contexts. Similarly, in Sweden, Professor Carl Johan Fürst (LCP6, Sweden) recalled that the process of translation into Swedish was relatively unproblematic. Dr Elisabeth Medicus (LCP 18) in Austria described both the use of the LCP documentation already developed and translated in Switzerland, and the process of registration required both with the Liverpool ‘home’ team and the German speaking ‘DACH’ collaborative. However, she reported that the term ‘pathway’ caused an issue in Austria for reasons that were not solely cultural or linguistic, recalling publication of a book called ‘*Dying in Peace’[[2]](#footnote-2)* that provided a critical perspective on pathways. The book generated some attention at the time the LCP was introduced in Austria, creating some sensitivities around use of the term.

Interviewees from Argentina, Denmark and the Netherlands described how they engaged in a process of both translation and cultural adaptation. In Argentina, cultural perceptions about the meaning and temporal associations of ‘dying’ and ‘death’, as well as the lack of significance and meaning of ‘Liverpool’ or ‘pathway’ for Argentinians, led to a completely new term being used. Dr Gustavo De Simone (LCP 3) emphasised the pre-eminent importance of the Spanish concept of death as a ‘moment in time’, and the cultural difficulty Spanish speakers might therefore have with the northern European notion that dying is a process. The solution was to use the acronym PAMPA, which stands for ‘*Programa Asistencial Multidisciplinario Pallium’* and also brings to mind the Pampas grass in the rural areas of Argentina. A secondary descriptor was then added, using the words: ‘*integrated care plan for patients* ***in*** *the end of life’* (LCP 6, Argentina our emphasis).

In Denmark, a cultural difference in the meaning of the term ‘dying’ led to an interesting ‘work around’, which Dr Svend Otteson explained (LCP 16, Denmark):

*So, when we’re talking Liverpool Care Pathway and the last 48 hours we had a problem with the terminology there. So, we used the terminology for a kind of making it easier for us - talking about* ***the dying-dying patient*** *(our emphasis).*

*I: I didn’t quite catch that. The dying?*

*The dying-dying patient. You have the dying patient – [what we call the] imminently dying or the dying patient as a definition. The dying patient has hours or a few days or a few weeks left. But when you’re talking about Liverpool Care Pathway you have probably two days left. So, there was a confusion around terminology using dying patient and the Liverpool Care Pathway using dying patient. So, to stress or to highlight that it was the dying patient in the Liverpool Care Pathway we used the term dying-dying patient.* (Dr Svend Otteson, LCP 16, Denmark,our emphasis)

A similar issue occurred in Japan, where the term *‘Mitori’* was used instead of a literal translation of the word ‘dying’ for cultural and linguistic reasons:

*…dying or death is very direct word. But in Japanese … we don’t use dying or died. But if I translate it, it is dying. And…*

*I: Okay. So what do you have there?*

*We say Mitori, Mitori. Maybe you can find the word.* (Professor Mitsunori Miyashita, LCP 10, Japan)

Translation and adaptation was further complicated in Japan because of the lack of perceived suitability of the flow chart for pain management in the UK version of LCP, for Japanese practice. For this reason, emphasis was placed on the concept of the LCP, rather than on the detail. The solution was to encourage clinicians working in different areas to develop their own flow chart based on the LCP example:

*I’d say it was difficult to agree with the translation, especially on this algorithm … (about) the usage of medicine. But at that time we did not have clinical guideline of pain management (and) … they could not agree with this flow chart… After I became principal investigator, we didn’t emphasise the flow chart. (We said) this is simply just an example* (Professor Mitsunori Miyashita, LCP 10, Japan)

In the Netherlands and in New Zealand careful attention was paid to the suitability of all the goals of care in the UK version of the LCP, and some revisions were made for cultural reasons. In the Netherlands this became necessary after the changes made in the UK version 12 introduced what was perceived as an unnecessary focus on clinically assisted hydration and nutrition at the end of life:

*We had a second version and that's based on version number 12 in the UK. But the difficulty between version number 11 and version number 12 is that there was already a lot of problems in the UK and therefore there were two new goals about fluid and feeding. It is a discussion we can't understand ... really understand in the Netherlands … so we didn't make it two different goals … we put it together with our judgement about, for example, oxygen and antibiotics, so it's part of another goal and not one itself* (Dr Lia van Zuylen, LCP 9, Netherlands)

In New Zealand it was perceived that cultural and spiritual care goals should be separated:

*In consultation with the Liverpool team, we had another goal added to the list of goals of care on the LCP and that was around cultural support and cultural care. That here in New Zealand we felt that putting spiritual care and cultural care together wouldn’t be appropriate, that we had those as separate goals of care…. There were some language differences ...and that did have an impact on how we taught people to use the documentation. So it did have some limitations around some of the language. But the [Liverpool] team allowed us to modify some language but not all language and that did cause some confusion at times, I think.* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

In Belgium and Italy, a very different set of circumstances prevailed. The research based approach taken there to the development, adaptation and trialling of a complex intervention based on the LCP meant that considerable changes and adaptations were made to the original LCP programme that went far beyond a strict translation of the core document. Dr Costantini in Italy (LCP 19) recalled that while the strict translation of the paperwork was relatively straightforward, the development of a detailed implementation manual - which he saw both as essential and lacking in the original UK model - was more complex. He describes how such a manual was developed based on the core principle that the implementation of the LCP in Italy must be led by a specialist palliative care team:

*We started with the idea of implementing the LCP as part of a research framework, as part of a research project. The first thing we did was the translation of the document, it was required by the international LCP group. They revised our translation and they accepted our adaptations. To be honest it wasn’t completely different from the original. In my opinion a care pathway is not just the document but also the way to implement the document. We didn’t change the document a lot just small adaptations which I have put in context but we probably changed a lot the way we implemented the LCP. First we wrote a manual for its implementation. We did all these things before receiving the answer from the Ministry of Health. The manual for implementation was based on the idea that the LCP had to be implemented by a specialised palliative care team. The palliative care team was responsible for the process of implementation and about the appropriateness of the procedures, of training about end-of-life of care and correct application of the LCP. So in our approach the specialised palliative care team was a necessary condition for doing that.* (Dr Massimo Costantini, LCP 19, Italy)

This approach was mirrored in Belgium, where the research team closely collaborated with the Italians, as well as the UK and Dutch teams, in the development of their intervention for use in geriatric wards. As in Italy, the main challenge was regarded as the development of a guide to implementation:

*So we started by talking to people in the Netherlands and also to Massimo Costantini in Italy, we knew he was doing a big trial in hospital with cancer patients so we went to Italy to talk to him and we went to the Netherlands to talk to those people and we also went to Professor Ellershaw’s group in the U.K. and we started with the various documents and the program and thought, well, what can we use, what is suitable, do we need to adapt this and how can we make this work in Belgium? … So the main challenge was thinking how we could implement it; this instrument in that specific setting because the LCP programs that existed- well there were language problems, for example with the Italian version, so we wanted to know exactly what was there and found really a very elaborate instrument and a guide. I think the main changes were in wording, but the main challenge was working out step-by-step the implementation guide. For the document itself, we did not make very many changes. We started from the LCP - Zorgpad voor de Stervenfase-RotterdamZS-r(lcp) - used in the Netherlands, and we mainly adapted the language and added some extra things for older people and some care goals.* (Dr Tinne Smets and Dr Kim Beernaert, LCP 15, part 1, Belgium)

***Use and diffusion of the LCP***

In all countries except Belgium, where an intervention based on the LCP was introduced during a research study into geriatric hospital wards by a steering group[[3]](#footnote-3), the use of the LCP was initiated by specialists in palliative care. However, across our interviews, there was considerable variation in where the LCP was first used, and whether this was solely in a specialist palliative care context, a generalist care context, or in both. Similarly, there was variability in the patient population targeted: in some countries (for example the Netherlands) the primary target was oncology care, in others (such as Belgium) the target extended into broader categories of patients approaching the end of life, such as older people with end stage frailty or dementia. There was also variatio according to whether the use of the LCP remained confined to one or two small local areas, or was diffused regionally or nationally, and the extent to which this was organic and unplanned, or strategic and systematic.

In this section we look at interviewees’ accounts of the care setting they targeted when they first starting using the LCP, the associated patient group with which they sought to employ the LCP and their accounts of the level of diffusion. Insights into the factors and mechanisms influencing the different levels and types of diffusion emerge from these accounts and are summarised in Table 2. They include the presence or absence of: some form of nationalised health care system, a national policy for palliative care into which the LCP (or a version thereof) was recommended as well as some level of integration of palliative care services into mainstream health care; funding for a programme of research on the LCP or its implementation; and a wider quality control or governance structure onto which the LCP could be grafted.

In those countries where there was no ‘national’ or centralised mechanism for the uptake of health care interventions, including elements of LCP in professionally endorsed guidelines for palliative care was regarded as the primary means of encouraging its use. In these cases, not only were numerous versions of the LCP forthcoming, contrary to the UK originators’ intent that the LCP should retain a standardised format, but the ‘spread’ of the LCP was relatively organic in form. Further, in these cases, its use was dependent upon clinicians to make an active choice to ‘opt in’. There was no element of compulsion as was the case in those places where its use was mandated under a national strategy.

**Table 2: levels and mechanisms of diffusion**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Local | Regional  (limited) | Regional (extensive) | National | Mechanisms |
| India |  | x |  |  | * Professional networking/ endorsement * Training |
| New Zealand |  |  |  | x | * Professional networking/ endorsement * Government endorsement * Funding by Government * National coordinating office * Network of facilitators * Training |
| Argentina |  | x |  |  | * Professional networking/ endorsement * Government endorsement * Training |
| Germany |  | x |  |  | * Professional networking/ endorsement |
| Norway |  |  |  | x | * Professional networking/ endorsement * Government endorsement * Funding by Government * National coordinating office * Network of facilitators * Training |
| Sweden |  |  |  | x | * Professional networking/ endorsement * Government endorsement * Funding * Training |
| Australia |  |  | x |  | * Professional networking/ endorsement * Government endorsement * Funding by Government * Regional coordination * End of life care champions |
| Netherlands |  |  |  | x | * Professional networking/ endorsement * Government endorsement * Funding by Government * Training |
| Japan |  | x |  |  | * Professional networking/ endorsement |
| Belgium |  |  | x |  | * Professional networking/ endorsement * Government endorsement * Funding by Government / health agency * Training |
| Denmark | x |  |  |  | * Professional networking |
| Switzerland |  |  | x |  | * Professional networking/ endorsement * Government endorsement |
| Austria | x |  |  |  | * Professional networking/ endorsement |
| Italy |  |  | x |  | * Professional networking/ endorsement * Funding by Government / health agency * Training |

*Local diffusion*

At one end of the continuum in terms of target of use and level of diffusion were Denmark and Austria, where in each case use of the LCP was narrowly confined to the initiator’s own specialist palliative care (SPC) unit. In Denmark, Dr Svend Otteson (LCP 16) described local implementation of the LCP, focused largely on his own SPC unit where it became a standard protocol for the care of the dying between 2009 and 2015. He subsequently described a time limited attempt to use the LCP in the general oncology wards located in the same building as the SPC unit, but this came to an end when the SPC unit closed. In his account, Dr Otteson provides interesting insights into some of the factors limiting further spread:

*So, we made our Danish version, but it was very close and we used it from A to Z, if I may say so. We were, what we would call, we were true to the Liverpool Care Pathway in any sense, and used it for a standout protocol for our dying patients from 2009 until 2015. And I think about 270 to 300 patients were on the Liverpool Care Pathway … Yes, as a standard protocol. But we started preparing, introducing the implementation in 2005 or 2006, something like that. But we were a rather new palliative care unit so we had to start all over, and that was the reason why it took some years before we started the Liverpool Care Pathway. We were in fact the first I think and also the only department or unit in Denmark at the time with the Liverpool Care Pathway.*

*I: So, it was local implementation rather than anything that was more regional or national?*

*Yes. We don’t have the same organisation as you have on a national basis … I had done a lot of teaching at Roskilde hospital and I had of course told about Liverpool Care Pathway all over Denmark. So, many people know about the Liverpool Care Pathway. But we thought about making a national centre for Liverpool Care Pathway or for the care of dying patients, but Britain I think has the culture or time or what you call it to do so. Because we don’t have an organisation where we just say now we do it on a national wide basis.*

*I see. So, you didn’t have any government support or wider organisational support?*

*Not at all, no* (Dr Svend Saalbach Ottesen, LCP 16, Denmark)

In a similar account from Austria, Dr Elisabeth Medicus (LCP 18) described how she used the LCP in her own inpatient SPC unit, working with some nursing colleagues and as part of the German speaking countries’ ‘DACH’ collaborative, which was led by Steffen Eychmüller (LCP, 17) who was working at that time in St Gallen, Switzerland:

*I: When did you make a start with using the Liverpool Care Pathway at work?*

*In 2008 we had a kind of a study group or a visit in St Gallen with … I think three, we went there, two nurses and me. Then we applied the registration in Liverpool also in 2008 and the registration in St Gallen which was … we had to do both registrations in this collaborative group and then we started, in 2009, to implement it in our institution, only in the inpatient palliative care, in the inpatient ward and we started with version 10 at that time* (Dr Elisabeth Medicus, LCP 18, Austria)

Dr Medicus goes on to describe how she tried to collaborate with staff in an Austrian nursing home once she became aware that they were using the LCP for residents with complex long-term conditions, however this attempt at collaboration did not develop and she was unaware of the extent of any wider use in Austria:

*I: So, you started using the LCP in 2009 in your inpatient unit and, as far as you’re aware, was it used in other places in Austria?*

*R: No, it’s a pity that it didn’t happen. No, not really true … once I went for a visit in a special care home near to us where they care for people in vegetative states and with tracheal cannulae, so it’s a little bit specialised nursing home with complex and chronic psychiatric disorders. I didn’t go there for … I just know the head doctor there and she invited me because they had built another ward and so I went there and I saw LCP in their computer [and] … so I was surprised. Even after, I think it was in 2014 or 2015, and then I ask her, “What about that? Do you apply this?” And she said, “Yes we do,” and then I asked for cooperation, how they cooperate, and she said no they don’t have any cooperation [around] LCP and she said that it was helpful for process of certification. And I offered her a cooperation, but she never embraced this offer. So, I don’t know what they really did with the LCP* (Dr Elisabeth Medicus, LCP 18, Austria)

*Limited regional diffusion*

Limited regional diffusion was described by interviewees from India, Argentina and Japan. India and Argentina were the only resource poor countries represented in the study and in each case interviewees described attempts to introduce the LCP into both hospices and general palliative care settings (with an emphasis on oncology patients) but these efforts were geographically limited.

The introduction of the LCP to India in 2006 was described as an initiative prompted by a UK doctor who had an elective in India, and as a collaboration between the Institute of Palliative Medicine (IPM) in Calicut and the Indian Association of Palliative Care:

*The Calicut people first, they were involved in getting Dr (name’s) help and then that was taken up by the Indian Association of Palliative Care, it was endorsed by the Indian Association of Palliative Care* (Dr Stanley C. Macaden, LCP 1, India)

Inspite of these endorsements, lack of funding meant that use of the LCP in India was limited to four discrete areas[[4]](#footnote-4). In Argentina, lack of funding and lack of a wider infrastructure for palliative care similarly circumscribed efforts to *‘spread’* the PAMPA programme based on the LCP beyond its original site in Buenos Aires. This was inspite of considerable efforts to engage practitioners from all over Argentina and other countries in South America in education and training about end of life care and the use of the LCP:

*So we have professionals, students, professionals from Argentina, the different provinces and also other countries from South America. And when we teach around this programme they like to implement it in their institutions. They like it very much but don't have the structure, or the political decision or the way to implement these kinds of programmes. Because again, the palliative care … probably they don't have a team, multidisciplinary team or it's just a doctor and a nurse for a whole province. So it's difficult to think at this time to implement this kind of programme …We had at the time the illusion that it would be a more spread programme. But till now we have one more hospital, one more home based care team or programme, and a hospice. The last to join is a hospice, a little hospice. But we have now five institutions involved in the programme* (Dr Vilma Tripodoro, LCP 3, Argentina)

Dr Tripodoro’s colleague Dr Gustavo de Simone (LCP 6) also gives an account of the process of spread in Argentina, describing how it was linked to education of physicians. He refers to the intent to expand the implementation of the LCP to Patagonia, while making it clear that at the time of the interview this had not yet occurred:

*And then, we were involved, as I have said, in education. Some physicians who attended our courses, and our Masters, who were on some teams who were interested in replicating the experience in their own places, in the inner country. The first experience outside Buenos Aires was in Cordoba. Where they, we put it into practice at the hospital, and also at the home care programme there.*

*I: Okay. So initially, one centre, and then to the hospitals. And then, some of the students pick it up and used it in different places.*

*Exactly. So now we are dealing with people in Patagonia, where they have good political programmes, and they are highly interested in dealing with the pathway. But still in the initial phase, not implemented yet.*

*I: Okay. So, in total, how many places will be there, in Argentina, that are using LCP?*

*Total, now, four* (Dr Gustavo de Simone, LCP 6, Argentina)

In Japan, limited regional use of the LCP was also reported. One of our two Japanese interviewees, Professor Miyashita, described how one of the pilot studies was successfully carried out following earlier piloting of the LCP in two SPC units. However, they found a number of problems associated with use of the LCP in general oncology wards. He reported that medical staff did not wish to use it, nurses were worried about recognising whether someone was dying and there was a lack of necessary resource to support and train staff and sustain the systematic implementation of the LCP:

*Then we tried to implement it for [the] general ward. But it failed. …Well it’s…I think it’s … implementation procedure or method was not good. Explanation and training was insufficient. … And the university hospital, lung cancer respiratory ward. We did it … university hospitals, lung cancer and oncology ward. And it was difficult to decide to use the LCP especially [in] lung cancer. Now, sometimes the … patient is at the end of life stage and we try … to start to use the LCP. But [the] physician[s] said no. … [and] the nurses … nurses are … were … nurses were also reluctant to use the LCP … we stopped the pilot test at university hospitals there*. *We tried to revise the implementation method. But at that time the LCP problem occurred[[5]](#footnote-5) in the UK. Then we stopped the project*. (Professor Mitsunori Miyashita, LCP 10, Japan)

Professor Miyashita (LCP 10) estimated that around 20-30 individuals from ‘*maybe four or five hospitals’* had used the LCP at some point in Japan, although it was difficult for him to be sure of the extent of wider use. There was also a circumscribed attempt to develop a home care version of the LCP. This was described by Dr Ai Oishi (LCP 11), a Japanese general practitioner who collaborated with Professor Miyashita. Dr Oishi had spent time in the UK and, on her return to Japan, found information about the Japanese version of the LCP on the internet. This prompted her to make contact with Professor Miyashita to request a copy of the Japanese LCP document:

*After I came back from … the UK, I found [a] Japanese website which is introducing Japanese version of the LCP. But at that time, they only had … they only had hospital version … ... I asked Dr Miyashita that I'm thinking of using it. And then I'm thinking of using it in a homecare setting and then I asked him if I get a copy. And I think Dr Miyashita said something like, it’s still not completed and I have to use it carefully or something. But I think … at that time, I was working in a very little clinic and then it was a part of my project as a trainee … homecare doctor trainee, so I didn’t get any official approval from authority or somewhere* (Dr Ai Oishi, LCP 11, Japan)

Dr Oishi’s intention to use the LCP in general practice in Japan came to partial fruition, as she gained experience of its use in the course of her homecare training:

*Well … the challenge was I think … I tried to implement it with nurses and then other professionals, not only by me, of course. It should be used to … it is supposed to be used by everyone. Without support from other people, I can’t…I knew I couldn’t implement it* (Dr Ai Oishi, LCP 11, Japan)

ProfessorMiyashita (LCP 10) described how he was asked by a member of the Japanese government about the potential use of the LCP nationally to improve end of life care: he advised the individual concerned against its incorporation into government policy because of his view that it was ‘immature’:

*And I … once I was asked by the government member but I said I … it’s immature how about LCP, she asked. And I … immature.*

*I: It’s not ready yet?*

*Yeah. You cannot incorporate it in national governmental policy* (Professor Mitsunori Miyashita, LCP 10, Japan)

*Extensive regional diffusion*

More extensive regional diffusion was reported from Switzerland, Germany, Belgium, and Italy. In Switzerland, extensive regional spread followed the work of Professor Steffen Eychmüller (the founder of the DACH collaborative) (LCP 17) in the Cantonal Hospital of St Gallen, who recalled that it was his intent from the outset to use the LCP to improve the care of the dying in general palliative care contexts. The translation of the LCP, and the development of an associated training programme, proceeded with this goal in mind. An opportunity then came to establish a quality improvement initiative in oncology care, in which care of the dying became one of the standards:

*I: At the time, were you intending that you were going to use the Liverpool Care Pathway mainly to improve care of the dying outside of specialist palliative care, if you see what I mean?*

*This was the clear goal and also to use the quality management circle that has been established in many surroundings in our German speaking world as a vehicle to improve care for the dying because the topic alone was not powerful enough. But if you combine quality management, quality improvements in hospitals together with such a topic, it worked* (Professor Steffen Eychmüller, LCP 17, Switzerland)

The subsequent broader regional diffusion that occurred in Switzerland was dependent on voluntary collaboration or ‘opt in’ by other providers of palliative care. Uptake was encouraged through work led by Eychmüller to include elements of the LCP in national guidelines for palliative care, which clinicians were encouraged to use to develop their own version of the LCP:

*In our country, we worked out and developed together with the other language regions like the Ticino [Italian] and Romandie, the French speaking part, a national guideline for how to deal with people and their family carers during the time of dying. This was mainly based on the competencies and knowledge we had from the Liverpool Care Pathway but it served more as a framework document so that different institutions, from hospitals to community care to nursing homes, could derive their own versions from this framework version* (Professor Steffen Eychmüller, LCP 17, Switzerland)

In Germany, initial use of the LCP also took place in SPC units. This was as a result of collaboration by German SPC practitioners in the DACH initiative led by Professor Eychmüller. Professor Raymond Voltz (LCP 4) reported that although some spread then occurred in general palliative care settings in Germany (especially in hospitals) its extent was limited, as in Switzerland, by the lack of centralised organisation of the health care system and no precedents for national implementation projects of a similar type. He observed that the recommendations from the Liverpool team for national implementation would ‘*never have worked’* and that its use depended on the personal initiative of *‘active’* individuals. As in Switzerland, diffusion was dependent on the inclusion of aspects of the LCP in German national guidelines for palliative care:

*Well, at the moment it's implemented in several …as far as I know in individual institutions around very active people. And once they leave the Liverpool Care Pathway is also dying in its use. So it's not really implemented by institutions I would say.*

*I: So it is not implemented at the national level like it was implemented in the UK but it is implemented…?*

*Because we don't have that national level at all as in the UK. It was much easier, it's a different healthcare system. It's very fragmented and regional over here, and so it would have never worked … We have national guidelines and especially I was, and probably this is the reason why you contact me, I was one of the coordinating people for our national guidelines [for] palliative care. One of its components is on the care of the dying, and what we have done there is to implement, if you want, this is some sort of implementation on a national level, the contents of the Liverpool Care Pathway is very much implemented there. So the whole chestnut in our national guidelines is built around the content of LCP. So actually this is the best as we can get on the national level ... It’s not actively used. I would say it's not more than maybe 30 [hospitals] or something like that* (Professor Raymond Voltz, LCP 4, Germany)

In Belgium, implementation of the CAREful programme[[6]](#footnote-6), based on the LCP, was reported to have extended to around 70% of hospital geriatric hospital wards in Flanders, following the completion and reporting of a cluster randomized trial of the latter. Implementation in each case was preceded by the requirements of registration and attendance at a two-day training programme. It was formally supported as an implementation and evaluation programme by the National Cancer Society, as described by our Belgian interviewees:

*So we aimed for 30% coverage but now we are already at 70 or 80% coverage.*

*I: … And you said that you have about 70% coverage now. Is that just in hospitals or are there other places where the LCP is being used?*

*Just hospitals. You see it’s not a funded programme it’s an implementation project funded by the cancer society (discussion in Flemish about the name) … all control wards after the intervention was finished also got the training, the implementation they could use. They could follow it for free, kind of. The ones that are now included in the implementation phase are all new hospitals ... I can also say now we already did, again, the two two-day training for the implementation stage* (Dr Tinne Smets and Dr Kim Beernaert, LCP 15, Belgium)

A similar process took place in Italy, where the LCP was evaluated in a programme of research that culminated in a cluster randomised trial on general medical and respiratory hospital wards and was followed by a time-limited period of broader implementation. This took place in hospitals in a number of regions in Italy. Implementation in hospices in one region, Liguria, also occurred after the formal trial. The research and implementation programme was led by Dr Massimo Costantini (LCP 19) from his work place in Genoa, under the auspices of the palliative care network of the Italian National Cancer Research Institute. Dr Costantini had gained funding from the Italian Ministry of Health and describes the early days of the research thus:

*When we did phase two we implemented LCP in three medical wards of Genoa and one respiratory disease ward in Genoa, in four wards, and we assessed the impact of the LCP before and after the implementation of the LCP. We published three papers in Palliative Medicine. One methodological, one with the results of before and after and one where a pool had been studied where we interviewed the professionals, physicians and nurses, before and after the implementation about expectation and the perceived efficacy of implementation and problems of course. The goal of phase two, as [reported] in these three papers, was to decide if we could start with a randomised trial. In the meantime, we received a positive answer from the Minister of Health and the project was funded. In phase two at the end of implementation we decided to slightly change the programme. We started with phase three but the structure was the same* (Dr Massimo Costantini, LCP 19, Italy)

A distinct characteristic of the process of wider implementation in Italy was that Dr Costantini strongly advised against use of the LCP in those circumstances where a SPC team was not in place in the hospitals requesting use of the intervention:

*…our LCP was different from other LCPs. The document was the same but I stressed a lot the way that a care pathway is not just defined by the document you use but also the way you introduce the document because it can make the difference. For example, after the publication of phase two we received requests for LCP documentation from different hospital wards in Italy. The first thing we asked them was ‘Do you have a palliative care team in the hospital?’ If no, our advice was before trying to introduce LCP introduce a palliative care team and then we can discuss about the LCP. That was our vision in Italy.* (Dr Massimo Costantini, LCP 19, Italy)

*National diffusion*

Norway, New Zealand, Australia, Sweden and the Netherlands all experienced a degree of national spread of the LCP, with a comprehensive range of patient groups and care settings targeted.

Interviewees from Norway (LCP5), New Zealand (LCP 2), and Sweden (LCP 7) described how the LCP was used first in hospices and then in a range of other general palliative care settings, such as hospitals and care homes. While the degree of centralisation of their health services varied, with New Zealand having a comparatively centralised system, compared to Norway, Sweden and the Netherlands, in all cases the broad extension of the LCP to general care settings was facilitated by a national body.

In Sweden, the LCP was introduced in 2007 as part of a national project monitored by a palliative care competence centre, with an estimate published in 2014[[7]](#footnote-7) that the LCP was in use in over 200 units in Sweden, including specialist palliative care, home care, hospital wards and nursing homes. Professor Carl Johan Fürst recalled that, even though Sweden (like Switzerland and Germany) was a ‘*very decentralised country’,* the LCP was used widely, known about on a national scale and included in Swedish national guidelines about palliative care:

*…. there are services all over the country using it in palliative care, but also in some nursing homes or care homes. It is actually used and I think, as far as I know, also in a few hospital wards … But, not everybody is using it, but everybody knows what it is. It’s also … you can read about it in the national guidelines, it is recommended there, although we have changed the wording a little bit in the later editions ...* *you need to know that the government in Sweden is not very … it’s not a very centralised country, it’s a very de-centralised country. So, the government, they can make some recommendations, but they cannot tell you what to do* (Professor Carl Johan Fürst, LCP 7, Sweden)

Professor Fürst also explained that in addition to Swedish national guidelines on palliative care which recommended the LCP, another mechanism of diffusion was via the quality indicators or parameters in the National Palliative Care Registry that were based on the LCP:

*… we have a national registry for palliative care, which is actually a registry where you register every patient after death. This registry is sort of retrospective and you look at the last week of life, how it was. This registry is covering about 70 per cent of all expected deaths in the country. The quality indicators or parameters in the registry, is very much taken from LCP* (Professor Carl Johan Fürst, LCP 7, Sweden)

In New Zealand and Norway, national co-ordinating offices were set up which enabled emulation of processes of implementation that had occurred across general care contexts in the UK. In New Zealand, introduction of the LCP into a hospice in Palmerston North following participation in a meeting of an international interest group for the LCP in 2008 and sparked a process of national diffusion marked by the establishment of a national LCP office in 2011:

*We managed to persuade the Ministry of Health that this was a good and useful, positive assist for good dying, if you like, in all settings and I suppose the question of quality was ... rang a good sound with them because there was some Ministry support for leadership and palliative care at the time, we argued strongly from our hospice that we should set up a national coordinating office as the best means of getting the unified and benchmarkable process across all of New Zealand. For four years or so we managed to succeed in that process with the setting up of a national office* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

New Zealand had an extensive existing infrastructure for palliative care and employed nurse practitioners sourced from district nursing services or specialist palliative care services to liaise with GPs in the community and enable to the use of the LCP in residential care settings and the domestic home. They called this the ‘palliative care partnership’:

*In terms of general practitioners and community, we have a special partnership which we call the palliative care partnership and with our general practitioners and specialist palliative care and it was through that mechanism of partnership and leadership from general practice that we were able to get a good uptake by general practitioners working with our specialist nurses from hospice and the district nursing service to apply a lot of pathways to home death as well* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

A similar level of infrastructure existed in Norway, where the LCP had been initially introduced in the early 2000s by a leading palliative care physician in the first palliative care unit in Norway. The LCP was then translated for wider use by our interviewee’s palliative care centre in Bergen and first used in 2007 in Bergen hospital and in a nursing home, before being taken to the larger University hospital in Bergen. A process of nationwide spread driven mainly by requests from other institutions for help then started. This involved the Bergen municipal area initially, and then other regions.

*So first we started in the first hospital, then we took it to the main university hospital in Bergen, and we presented it to the management and they were very positive. And we decided on some wards where we wanted to introduce it first, and try it out. And we applied for money from the Norwegian Medical Association and from the health authorities. And they were all very supportive, and we started a project. And then we had all these requests from the rest of the country. “We have heard of the LCP somewhere and we want to start using it, can you help us? We've heard that you have a translation”. So it just added on. And we never really promoted it. We never really went out to advocate it, it spread by itself.* (Professor Dagny Faksvåg Haugen, LCP 5, Norway)

Professor Faksvåg Haugen described the diffusion of the LCP in Norway as national, although she pointed out that, as in some of other countries, there was no compulsion for its use at a national level:

*So very soon it spread to other regions of the country. So you can say that it was a national implementation or a national spread because it is used in all parts of the country. A national spread I think is better.*

*I: Was there a national level implementation or was it more local and regional level of implementation?*

*Yes, there is no national policy or guidelines stating that it should be used. But national guidelines presented it as an option for good care of the dying. It's from the Government … in what is called the National Action Programme for Palliative Care in Cancer* (Professor Dagny Faksvåg Haugen, LCP 5, Norway)

Despite the lack of a national mandate for use, Professor Faksvåg Haugen described how Norway was able to follow the New Zealand model in developing an implementation infrastructure around the LCP, using grants gained from the Norwegian National Action Programme for Palliative Care in Cancer:

*… we have networks of palliative care nurses and cancer nurses in most parts of the country. So we have these resources in every nursing home, in every home care district. So we had sort of a good basis for the spread. There were people who could be ambassadors and advocates and also who could do the training and education around. We had in really many places a very good structure to use. And then there have been a lot of funding opportunities. I already told you that we had funding from different sources, the Medical Association, the healthcare authorities, the Directorate of Health and the hospital. Many projects all over the country receive[d] money from the state for implementation. And we did a survey and we found that about 20 per cent of all users had had specific funding to implement the LCP …* *the funding also gave us the possibility for a position for a network coordinator who worked on a national level* (Professor Dagny Faksvåg Haugen, LCP 5, Norway)

In Australia, a scenario occurred that was very similar to New Zealand and Norway. The LCP was widely used, especially in the states of Victoria and Queensland, with some aspects of it disseminated nationally in residential aged care. In Melbourne, Victoria, Dr Mark Boughey (LCP 12) recalled that soon after he took up his post at St Vincent’s Hospital he had contact with a nursing colleague who shared his interest in finding ways to improve care of the dying outside of specialist palliative care contexts. The nurse had set up a special interest group with representatives from the state of Victoria. The group considered the LCP as a key means to achieve its goals. Its work over a three-year period to develop an Australian version of the LCP that was *‘congruent’* with the principles of the UK intervention, and quickly drew the attention of state health policy makers in Victoria, where a quality improvement initiative focused on acute care settings was under development:

*One of the nurses there was actually, just at the beginning [of] forming a special interest group to bring together people who are interested in trying to look at improving care for dying people that are not necessarily connected to specialist palliative care … they’d got interested people from Melbourne and around Victoria together to talk about this very issue and that’s when the LCP really came to the table. I started my job at St Vincent’s in 2008, so about 2009, fairly early on, when that was being discussed … And it really got the attention of our policymakers in our state government, who wanted to … saw this is a very key part of Victoria being ahead of the game* (Dr Mark Boughey, LCP 12, Australia)

Dr Boughey goes onto describe the LCP project in Victoria as a ‘*clinician-driven initiative supported by the government’* that quickly spread throughout generalist services, with an emphasis initially solely on acute care, including the stroke clinical networks. Dr Boughey perceived that the LCP project in Victoria had a synergy with the wider focus of a State-based quality improvement programme in acute care. This ultimately resulted in the introduction in hospitals of a series of quality measures for end of life care:

*In 2016 it was actually signed off by the health minister that the acute health service had to demonstrate how they were implementing care plans for the dying into their health services. It was a measure that was directly reported by the CEO of the hospital to the health minister. They had a series of quality measures that they had to report against in end of life care* (Dr Mark Boughey, LCP 12, Australia)

Dr Boughey also perceived that the project in Victoria both shaped and reflected similar work in acute care contexts going in other Australian states, although he reflected that Australia never achieved a national approach or mandate for the use of the LCP. This was recognised in the Australian National Strategy for Palliative Care 2010, where a call was made for an integrated approach to end of life care across all care sectors[[8]](#footnote-8). Later in his interview, Dr Boughey reports that a ‘*pared down’* version of the LCP, developed without reference to the Liverpool team of original innovators, was widely introduced across Australia in residential aged care. This was because of funding from the Commonwealth Government in Australia, which is responsible for aged care. In a similar account, our other Australian interviewee, Associate Professor Carol Douglas, reported how in Queensland the LCP was used across general hospital settings in 17 service districts:

*Queensland Health had decentralised to 17 … you probably appreciate, Queensland is a very large place and it was decentralised to 17 HHSs, or Health and Hospital Services. In consultation with Queensland Health, and given that we had not had any reports of problems, you know, I mean significant problems, in relation to the use of it, they sanctioned the continuation of what was then the Care of the Dying Pathway given that each hospital committed to appropriate governance, education, et cetera. So, it rolled on* (Associate Professor Carol Douglas, LCP 8, Australia)

As we have seen, in the Netherlands, Dr Lia van Zuylen (LCP 9; LCP 14) was first introduced to the LCP in the early 2000s when she met Professor John Ellershaw, who had a visiting position in her Department at Erasmus Medical Centre (MC), Rotterdam. Dr van Zuylen’s Head of Department encouraged her to take a research based approach to the adaptation and use of the LCP. This started with a pilot study in the Erasmus MC, a nursing home and a hospice and was followed by a larger scale study in eight institutions. By the time of her second interview with us (LCP 14) in November 2018, Dr van Zuylen reported that since 2009, the Dutch Comprehensive Cancer Centre Netherlands (CCCN) had become the national implementation *‘machinery’* of the LCP via 67 regional networks[[9]](#footnote-9), using training and telephone to support interested clinical teams. She also described how the LCP was an opportunity to test out whether an intervention could be implemented on a national basis as the structures of the CCCN gradually evolved:

*I: And I understand that you were able to get the Dutch Comprehensive Cancer Centre to support the use of the Liverpool Care Pathway. Could you tell me a little bit about what happened then in terms of the implementation, once they decided to promote it as a priority?*

*From the beginning, we worked together. And then there was a little bit of a different situation than it is nowadays. Nowadays the Comprehensive Cancer Centre, is a national Institute. When we started, there were several regionally organised CCCs, which had some link with each other but worked independently. So we started with our Comprehensive Cancer Centre to discuss this project and I asked them to get involved in the implementation of the LCP. They agreed on that. From the beginning, there was a good match between the employer of the regional CCC and the researcher. Together they did a good job in research on and implementation of the LCP … The moment the regional CCCs become one national organisation, the CCCN, the results of this project were known and we proved the effect of the LCP. So, the CCCN agreed with us that it was important to implement the LCP on a national level and that this project was important also for them as a new organisation.. After more than 10 years, we still work together. The implementation rate fluctuates as it’s organised bottom-up meaning that the health care organisations decided if they want to use the LCP and if they need help to implement.*

*I: Oh, I see. And the help that they get, is that financial help from…*

*No.*

*I: …from the government? No.*

*No, it’s just that someone from the health care organisation can follow a 2-day course on implementation and that there is some kind of telephone guidance* (Dr Lia van Zuylen, LCP 14, Netherlands).

This adoption of the LCP by the CCCN resulted in national spread, but the voluntary engagement of clinical teams (and some uptake outside of the structures of the CCCN) meant that it was not possible for Dr van Zuylen to be entirely sure about the extent of this:

*I think that it is around 200 organisations using it now, but I can't give you the exact figures.* (Dr Lia van Zuylen, LCP 14, Netherlands).

***Perceived benefits of the LCP***

*A systematic approach*

As noted earlier, most respondents anticipated that the introduction of the LCP would lead to a systematic approach to end of life care. This was an aspect of the LCP that went on to be highly valued once it was introduced into practice. For example, in Austria, Dr Elisabeth Medicus described positive impacts in a specialist palliative care unit on the process of decision-making, especially in relation to the diagnosis of dying and of symptom control, and on communication with patients’ relatives:

*I think that, in our team, which was composed of really committed people, everyone liked that it gave us a, kind of, security and it was also … so that clear decisions, it brought us clear decisions about ‘this patient is dying or not,’ that the symptom control was better, I would say. After all the body failed, but the symptom control for a dying patient, the assessment and the control was improved and that we didn’t overlook anything of importance, I would say. Also, I would say that there was advance care planning for frequent symptoms in the dying process. This was especially helpful for nurses and also for us as doctors, because then the nurses didn’t need to call us to withdraw an oral medication or something like this. So, for everybody it was easier and, sort of, valuable. Also, a brochure we wrote, also in cooperation with St Gallen, for the relatives and they got this, how do you say, this brochure?* (Dr Elisabeth Medicus, LCP 18, Austria)

Some interviewees described how they came to realise that the LCP also provided a systematic framework for teaching students about end of life care, even where there were limited opportunities for its wider implementation as a clinical practice ‘tool’. Thus, again in Austria, Dr Elisabeth Medicus recalled how useful for her teaching she found the ten principles of the LCP and then later, the recommendations of the Neuberger review[[10]](#footnote-10):

*Well, in preparing, the preparation of the teaching where I used the Neuberger review, but I very often use the 10 key elements on the best care of the dying, in teaching because this is very compact message for many professionals* (Dr Elisabeth Medicus, LCP 18, Austria).

In Argentina where implementation and diffusion of the LCP was limited but education a key part of wider efforts to build palliative care in the whole of South America, this element was particularly important, as Dr Simone explained:

*… on courses we've done specific sessions on the LCP, just to, as a way of teaching about end of life care. It doesn't mean that all the students will implement it, because they need to have the systematic approach, all the phases, et cetera. But they learn how to deal with end of life care, through the LCP, or the PAMPA ….*

*I: Right, so it provides a systematic approach for teaching end of life care.*

*R: Exactly* (Dr Gustavo De Simone, LCP 6, Argentina)

In contrasting circumstances, in those countries where the LCP was implemented on a larger scale, the process often provided opportunities for targeted education in ethically challenging areas of end of life care, such as clinically assisted hydration and nutrition. This was the case in New Zealand:

*… when we were implementing the LCP we were using that as a time for educating clinicians on the importance of communication around hydration and nutrition. So it was a wonderful tool and it did give people a wonderful opportunity, i.e. [to] give increasing knowledge about the benefits and burdens of artificial hydration or nutrition and to look at the ethical issues around that and then to look at the real importance and need for communication around that* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

*Interdisciplinary communication and positive impacts on nursing work*

Many respondents described an unexpected benefit from using the LCP, namely a positive impact on communication and interdisciplinary team working. In a related sense, its value in helping nurses to work more effectively and on an equal footing with medical staff was emphasised by some. For example, Dr van Zuylen in the Netherlands perceived that it gave nurses both confidence (because of its structure) and a new language to speak about transitions to end of life care with medical colleagues:

*... [nurses] they don’t forget things. They can show it to other people, they can tell new employees how to manage the work in the dying phase …They know when they have to talk to the doctor … I think another thing is that it gives them the possibility to ask the doctor, “don’t we have to start the dying pathway”? Because I think when they say to the doctor, “isn’t this patient dying” that it was more difficult for them to say than to ask don’t we have to change our care?* (Dr Lia van Zuylen, LCP 14, Netherlands)

In Denmark, Dr Ottesen described how association of the LCP with nurses’ work changed the power balance in terms of who directed patient care between nursing and medical staff:

*I: You said that the nurses were keen on the use of the Liverpool Care Pathway.*

*Yes.*

*I: Why do you think that was? What was it about it that they liked?*

*The structure of the Liverpool Care Pathway. It’s a working paper so they didn’t forget anything. So, they were very keen to use it. The doctors were not very happy because their wish for using Liverpool Care Pathway when the patient was dying was coming from the nurses who told the doctors that they had to use Liverpool Care Pathway now. Even so I had to teach the doctors throughout the whole period for the Liverpool Care Pathway, the new doctors and the old ones, but it was still the nurses who went in front and went, “now we have to use the Liverpool Care Pathway”* (Dr Svend Ottesen, LCP 16, Denmark

Dr Elisabeth Medicus in Austria also perceived that the nurses on the palliative care unit in which she worked were the key to the implementation process:

*I realised that it was very important to have a good implementation process in the team and we did do it by the engagement of the nurses* (Dr Elisabeth Medicus, LCP 18, Austria)

Similarly, in Switzerland, Prof Eychmüller described how the LCP generated enthusiasm and competence in the care of the dying among nurses, one aspect of which concerned new procedures to ensure the prescription of ‘as required’ (PRN) medications. This drove the implementation process forward, in spite of a lack of enthusiasm from other stakeholders:

*… nurses have been very welcoming. They loved it. They felt very much prepared. They supported it very well also in terms of personal centre training. A far more difficult client was the head of the department, so the chief officials that demonstrated the board but never showed up. But it was, in the end, really driven by the nursing competency. I think many of the evaluations we did later on also within the quality management brought up that the competency level of nurses was far higher compared to the ones of the physicians.*

*I: What was it, do you think, that the nurses particularly liked about the LCP?*

*The LCP established the framework and also established the rules that doctors have been obliged to prescribe many drugs for PRN medication for the last days of life. This was what they usually missed. It was this endless discussion about please prescribe a little bit of this and this drug and this really changed a lot* (Professor Steffen Eychmüller, LCP 17, Switzerland)

***Challenges and drawbacks associated with the LCP***

Here we report on the most notable challenges discussed by interviewees. In addition to these, some practical issues were also highlighted mainly to do with the difficulty of adapting the paper-based LCP so it could be used in electronic records or in the day to day management of the documents in clinical settings where staff were unfamiliar with the LCP.

*Scale of education, training and workforce requirements*

Interviewees perceived that wider societal and clinical understandings of palliative care constrained the extent to which it was possible to introduce the LCP. This was difficult in all of the countries, but especially so in the resource poor ones. For example, in India, Dr Stanley C. Macaden highlighted that neither patients nor clinicians had a clear grasp of palliative care principles, making its introduction very difficult:

*…the main thing is palliative care is not well understood by our own colleagues … [and] … a lot of times patients don't know what palliative care is, they think it’s another way of some cure, so they’re willing to grab at any straw* (Dr Stanley C. Macaden, LCP 1, India)

At the other end of the continuum, most of the other comparatively resource rich countries had seen a high profile given to palliative care across policy, practice and public spheres. This meant that there was fertile territory into which to introduce the LCP, as Professor Dagny Faksvåg Haugen, from Norway described:

*… palliative care has had a high focus in Norway for many years and we have done a lot to improve skills and knowledge and influence attitudes* (Professor Dagny Faksvåg Haugen, LCP 5, Norway)

These wider understandings influenced in turn the extent of the training and education challenge perceived to be associated with introducing the LCP. However, whether respondents came from resource poor or resource rich countries, they regarded this as both the most important determinant of scale or level of implementation and the most difficult aspect to sustain, with hospital settings identified as the most challenging environment. For example, in New Zealand, lack of confidence and training among hospital clinicians in communication skills related to end of life care were described as a *‘core challenge’* to the whole project of introducing the LCP:

*When it came to hospital settings, the challenge there was ... and I’m now looking retrospectively to some extent, it really was hitting to the core challenge of communication around death and dying and the lack of desire by clinicians to go there, the lack of confidence and training in that area and really reflecting the poor way in which death and dying was done and to some extent still is done in a hospital setting* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

In the resource poor countries of India and Argentina, the scale of the clinical educational challenge was exceptional: lack of resource was compounded by lack of wider awareness and rapid turnover of staff:

*The challenge, first of all, is the way to train the team, the different teams. And when the training is done I think the challenge is to train more people the next year, or the next time when people change and new doctors come or a new nurse comes, and we have to start again* (Dr Vilma Tripodoro, LCP 3, Argentina)

*… this is where the problem is because junior staff and nursing staff also, doctors and nurses at the junior or the middle level they keep changing and they keep going. And unless you are very knowledgeable about that and aware that this will happen, just because you’ve trained, done a fantastic training for one set of people you have to do the same thing again. Once you do that it’s a regular thing then you can get results. Training is key in this (*Dr Stanley C. Macaden, LCP 1, India)

The challenge of rapid turnover of the clinical workforce was also shared to some degree by respondents from resource rich countries. Where funding was forthcoming from governmental sources, it was possible to ameliorate this challenge by creating facilitator networks, gaining funding for dedicated posts for nurse practitioners or nurse consultants, or using the model of practice ‘champions’. As we have seen, it was sometimes also possible to capitalise on quality improvement programmes already in place that had a much broader focus than end of life care. Australia was a case in point:

*One of the things that we did over time, was that I did identify a champion for Care of the Dying [in each ward]. We would pull together those individuals from the different wards once a month and provide in-depth education. Then, they would go back to provide that education to their nurses, because it’s just not possible to provide education to every nurse on the wards. That works very well* (Associate Professor Carol Douglas, LCP 8, Australia)

*… [the] acute health environment, [which] already had a very strong national quality framework built in, even though it didn’t have specific criteria for end of life care or dying. We were quite familiar with having national quality cycles, the four-year cycle, two-year internal use per year for a four-yearly cycle of quality improvement and introduction of documents and care plans, pathways needing ongoing review. So, for the rollout and education and the orientation and adoption of these things … it’s already getting robust so systems are already in place* (Dr Mark Boughey, LCP 12, Australia)

Involving senior medical staff in education and training initiatives was often found to be difficult by all interviewees, even when funding was available for the purpose. An example of this was manifest in the large scale research based implementation and evaluation of a version of the LCP in Belgium:

*I think the main challenge was getting the physicians involved and especially in the training …The PhD student that was working on the trial had sleepless nights over it- she had had enough of it after four years … That’s always the hardest part, to find physicians, like for nurses and other staff, they are mostly motivated. But to find the physicians to take two days’ time to come to a training, it’s often more difficult* (Dr Tinne Smets and Dr Kim Beernaert, LCP 15 part 1, Belgium)

*Tensions between standardisation and variability*

Some interviewees reported that a significant drawback of the LCP was the tension that arose between the need they recognised to alter the LCP (so that it made sense in their context and culture or in the light of their experience) and a desire for standardisation. The latter came partly from their concern to align themselves with international colleagues by use of a standard LCP ‘tool’ and partly from the concern of the Liverpool ‘home’ team to maintain ‘quality control’ over the translation and adaptation process. Professor Raymond Voltz (LCP 4) captured this tension in his recollection of the development and use of the LCP in the German speaking countries:

*Well, one of the challenges initially and still is, is that it is very formal to use it. It's very formalised and it used to be very UK dominated and driven. And so initially it was not possible to change any single word. I would say this is a real hindrance to using it as an instrument I would say … it could not be locally adapted, you could not use it. You had to get registered in a very strict form. And so following all these steps. And sometimes I had the feeling that the emphasis of the group was more on the formalised technical aspects than on the content, and improving content. And that was personally for myself, but also for many people I know, it still is a very counterintuitive… If this was used in an open way, just everybody could use it, and then we could collect and grow and learn from each other. It was not meant to learn from each other, the experience, this was just meant to get distributed 100 per cent as it is* (Professor Raymond Voltz, LCP 4, Germany)

The withdrawal of the LCP in the UK and the associated freedom from Liverpool copyright requirements led to quite considerable adaptations of the original documentation. In some cases, it was clear that variations of the LCP pre-dated the UK withdrawal. For example, in Victoria, Australia, Dr Boughey recalled that as the implementation process unfolded, extensive use of the core LCP idea was employed locally by service providers to develop a variety of end of life care plans (especially in residential aged care) that were relevant and useful:

*…the LCP was pinched and rebadged and reimaged a little bit by a lot of services for their own usage. A couple of the tools that were developed were really the LCP, but, you know, pared down or for a modified form* (Dr Mark Boughey, LCP 12, Australia)

Similar situations occurred in New Zealand and in Switzerland. In New Zealand, implementation spread from one locality through clinical networks to several areas. Our respondents described how each area made ‘*their own mark on it… we had various documents that resembled LCP but I would think it would be fair to say there were at least a dozen in operation in New Zealand’ (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)*. In Switzerland, the development of regional and local versions of the LCP was encouraged as long as these addressed the key principles and competences of a palliative care guideline produced by the DACH collaborative and inspired by the LCP. In this way, national spread was encouraged in spite of a regional government structure:

*There are some core elements now in the best care for the dying that John [Ellershaw] formulated. This is also the core of the framework but the adaptation to local factors and local behaviours and local guidelines they may already have in place, this needs to be offered. So if we [were to] come in with a national standardised document and [say] everybody needs to do it, this does not correspond with our Swiss idea of building up competencies. It's not a national health systems approach. It's a very much a local regional approach* (Professor Steffen Eychmüller, LCP 17, Switzerland)

*Misgivings about lack evidence base and understandings of optimal implementation process*

In Australia, Dr Mark Boughey recalled that while the rapid spread of the LCP throughout Victoria and other States was associated with the expression of some misgivings about a lack of research evidence, these were quickly overwhelmed by the enthusiasm for the LCP as a means to fill a ‘gap’ in end of life care in non-specialist settings:

*… people were raising questions about, you know, “Where’s the evidence?” And so forth, but in practical terms, it was seen as a … it was filling a gap that people recognised in demonstrating good care at the end of life*  (Dr Mark Boughey, LCP 12, Australia)

Other respondents, such as those from New Zealand, acknowledged that while there was a lack of narrowly clinical evidence for the LCP from their own countries they were reassured by awareness of research taking place elsewhere:

I: *The other point raised here was that there was no robust evidence of effectiveness. Were there any such issues raised in New Zealand?*

*We had done some research around the implementation of the LCP in New Zealand initially. However, that wasn’t actually an issue in New Zealand in terms of robust evidence. I think because it was new and the evidence was emerging and there were still studies, and there was the Italian study as well that was going on. So we knew there were studies, yes, it wasn’t a big issue, there wasn’t an issue raised here* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

Our respondent from Norway, Professor Dagny Faksvåg Haugen, described her perception of a critique of LCP, focusing on the debate or conflict as she understood it about whether one category of dying people is similar to another, and describing an attempt to build a consensus position around this issue:

*… but we've had some challenges from … well, what should I say, especially one physician and a small group of physicians later on. And that has really been our very main challenge. That said, they think that the LCP is not suited for persons with dementia. They are not opposed to the LCP per se and support its use in care homes for patients. But say that the plan has not been sufficiently validated in persons with dementia. And the leader is a former nursing home physician but now she is a researcher and head of a research centre for nursing home medicine. …. But, then we had taken this, well, I don't know whether I should call it conflict, to the Directorate of Health. And we had a national meeting with this other group and with us, and we had a lot of discussion and the conclusion was there is really no reason to warn against the use of the LCP in persons with dementia. Because a dying patient is a dying patient. All dying patients need care. And we think that in the dying patient individual differences are really much greater than differences based on diagnosis.* (Professor Dagny Faksvåg Haugen. LCP 5, Norway)

As we have seen, respondents from Belgium, the Netherlands and Italy, expressed a primarily research-based rationale as the primary motivation to develop the LCP for use in their own countries, recognising from the start that research evidence was a necessary precondition for use of the LCP. However, in each case, they came to the realisation from their research studies that the processes of staff training in palliative care and in implementation of the LCP were just as important as any other types of data:

*I think it was important you don’t have distributed the program - you should really make them follow a training programme and I think the main issue in the UK was people can just use it without any training or implementation process to follow whereas here [in Belgium] people have to register to get all the materials and we educate them how to implement it* (Dr Tinne Smets and Dr Kim Beernaert, LCP 15, Belgium)

*I was always very keen on saying “please be careful”. It’s not about using a care pathway, it is about caring for people who are dying. And it is not about that you have to tick the box, [but] you have to know what you are doing in your care for the patient and the relatives (*Dr Lia van Zuylen, LCP 14, Netherlands)

Dr Costantini from Italy (LCP 19) described how he was aware of the problem with regard to lack of guidance and knowledge about implementation from the start of his work with the LCP:

*I didn’t understand very well the way the LCP was implemented in the UK. I didn’t know and to be honest I’m a clinician as well, I’m a researcher but I’m also a clinician, and I was aware that training about the last days of life seems easy but it isn’t. So the risk of the cooking manual, can you understand what I mean with ‘cooking manual’*?

*I: Yes I can.*

*The risk of the cooking manual is that it’s very easy, it’s not a problem just reach for the drugs and so on, the risk was very high. So I wanted the palliative care team as a sort of guarantee for the appropriateness of those courses. To be honest the international group had nothing to do and nothing against the Italian choice. I always asked for the manual for implementation but I realised that the UK group, the Liverpool group, didn’t have a structured manual for LCP implementation. That was in my opinion one of the big problems of the LCP, not just the documents but the way you implemented them* (Dr Massimo Costantini, LCP 19, Italy)

Dr Costantini recalled his realisation that the process of training the specialist palliative care team (he describes how he expected them to *‘drive the car’* of the process) to lead the implementation in the general wards was going to be both lengthy and complex. It was this realisation (together with the additional implications highlighted by the UK wide withdrawal) that was a key determinant in the subsequent recommendation to withdraw the LCP from general use in Italy. Dr Costantini drew a stark contrast between the Italian insistence on the close involvement of the specialist palliative care team and the lack of emphasis that he perceived had been placed either in the detail of the implementation process or on the relationship between specialist palliative care team and general care context in the UK.

Professor Raymond Voltz (LCP 4) from Germany expressed a similar view at some length, commenting that what was required was research in the health services paradigm into the implementation process:

*I: Another major issue [in the UK] was that there was no evidence of its effectiveness before it was rolled out nationwide. Was that an issue ever in Germany? Did anyone raise this issue?*

*No. And as with many other things in medicine I think, we have so many methods in medicine or use of tools where we know they work, where we know they are right and they are helpful. And so we would never do a study on that. Of course, it would have helped maybe, but having said that, this was not the problem I think [in] the UK.*

*I always take the LCP story in the UK as a perfect example for the problem of getting the second translation. So the second translation from clinical studies into real world. And so even if you have done good clinical studies, like Massimo[[11]](#footnote-11) was, of course trying with his randomised control trial in Italy, and he tried to get some more clinical study data. And that was of course … [but] even if in the UK you had done this you could have never … it would have never … and even if the primary endpoint would have been positive because you would've studied it in a warm, academic, palliative care environment, this is different from health service research going out into the field, into everywhere and rolling it out nationally. I think this has not been done.*

*And I know there have been comments on the data we're missing. But I think the problems around LCP were how it was perceived, how it was not implemented well everywhere around this delicate and existential problem of caring for the dying. So it tells us a lot that we need health service research. Clinical study data would have helped. But it would not have prevented the LCP disaster in the UK.* (Professor Raymond Voltz, LCP 4, Germany).

Dr Vilma Tripodoro from Argentina drew a parallel between what was required in implementing the LCP and implementation of other aspects of clinical care such as the use of nutrition or antibiotics:

*Of course, in general in medicine, well implemented, the use of antibiotics, et cetera. Well implemented, the use of nutrition, et cetera. So of course [when] badly implemented [this] is not a good tool or treatment or whatever. So, I was a bit angry about this report [Neuberger] because the problem is implementation* (Dr Vilma Tripodoro, LCP 3, Argentina)

Dr Tripodoro’s colleague from Argentina, Dr Gustavo de Simone, agreed with this standpoint, indicating that it was unrealistic to expect clinical practice in palliative care to be underpinned by narrowly research-based evidence and expressing the view that consensus, expert opinion and clinical experience were equally as important:

*…we work in clinical practice, and we assume that most of our practice are not so strong in evidence base. And it's a mix of evidence based, and consensus, and expert, and experience. And we still consider the LCP to be an important document, in relation with, like I said in the beginning. But of course, it's not perfect, at all. It's true that we should improve our knowledge and approach in a topic that is not so easy to perform research, you know* (Dr Gustavo de Simone, LCP 6, Argentina)

Professor Carl Johan Fürst (LCP 7) from Sweden explained that trying to gather robust and comprehensive clinical evidence for a complex intervention like the LCP was both disproportionate and showed a lack of understanding of the context of practice:

*But, to create evidence for a very complex intervention, so that the evidence is robust for positive effect of the whole thing … it’s so difficult and so resource consuming, that … I mean, it’s almost impossible. To demand that is, I think, a bit out of context*. (Professor Carl Johan Fürst, LCP 7, Sweden)

***Perspectives on the withdrawal of the LCP in the UK and its consequences***

Interviewees were asked how they had felt when they heard about the withdrawal of the LCP in the UK following the recommendations of the National Independent Review, and what their reflections were on the implications for the use of the LCP in their own country. Many interviewees were deeply troubled and angered about the turn of events. This was for two main reasons. Some felt that the conclusions of the independent review were irrational because they covered territory that was much broader than the scope of the LCP on the last days of life. Others felt that Professor Ellershaw had been badly let down by his own colleagues, who sought to take advantage of the ballooning critique in the UK to further their own research portfolios. Professor Voltz in Germany and Professor Fürst in Sweden expressed particularly strong views:

*Absolutely shocked and not understanding what was going on in the crazy UK. Because of course we thought oh wow, this is a great thing, that a palliative care tool is now used nationally. Great. And this is an advancement of palliative care using it nationally, thank God that the UK has such a national healthcare system that they can do these things. We would love to have the same thing. This was the initial approach. And when we heard we were shocked. We were just shocked. Did of course not understand it at all what happened there. And poor John and his group, I mean they were really devastated and we felt very, very, very sorry for them. And it was just very unfair what has happened to them. And it was very unfair how it was treated, even from other groups within palliative care, as we were talking earlier. They used it for argumentation of their own research projects which was not fair at all. So that was really felt very, very sorry for the Liverpool group and this was absolutely unfair* (Professor Raymond Voltz, LCP 4, Germany)

*What the hell is going on, what are they doing, what is this? I didn’t understand, at all. I understood, very well, the debate, the media and all that stuff. But, for me, it was like a blame game, where you had to blame somebody and that blame was on the LCP. I think that was very, very bad. I don’t understand how you can blame something that is made to promote good care of the dying and, if it is misused, you blame it. I mean, if morphine is misused, you don’t blame morphine, you blame the clinician or something like that. If an operation is done too much, it’s not the problem with the operation, it’s a problem with the surgeon. This is the same, I think. So, I was very upset and I didn’t understand how this was going on, how it was … that it was sort of accepted by the medical community and even, you know, driven by parts of the medical community. I don’t understand it* (Professor Carl Johan Fürst, LCP 7, Sweden)

After expressing their initial reactions, interviewees became more reflective, seeking to communicate their thoughts on the underlying reasons for the problems in the UK and the actions they had taken to avoid these in their own countries. Many of these lessons had already become clear in their own work over the years in working with the LCP and have already been described above: they concerned the realisation that training, implementation processes and strong governance were essential. In some cases, interviewees came to the realisation that a close and sustained relationship had to be maintained between specialists and generalists in palliative care. All these prerequisites required funding and sustained co-operation and collaboration. For example, in New Zealand, interviewees reflected that the ‘storm’ in the UK was surprising but not entirely unexpected. They reflected that as well as exposing the power of the tabloid press in the UK, it revealed a key weakness in the UK version LCP: that it apparently prioritised ‘paper rather than principle’:

*Well, to some extent, unbelievable and yet believable, you know, tabloid press believable. The storm, however, was a bit unbelievable. My reflection is that it exposed the lack of national and regional coordination of this very important tool, i.e. promotion of the paper but not the principles which I think we picked up on very well.* (Dr Simon Allan and Bridget Marshall, LCP 2, New Zealand)

A similar emphasis on principle not paper was manifest in the accounts of other interviewees, as a key reason why they had managed to avoid the problems experienced in the UK. As we have already seen in the DACH collaborative countries, this emphasis, which was in any case necessary because of the lack of a centralised health care system, meant that the LCP was used as a framework of national guidance on palliative and end of life care but was then subject to local interpretation on the ground. Professor Steffen Eychmüller reflected on the differences thus:

*Actually, we had many discussions in our German speaking collaboration, with the Germans and the Austrian people. For us it was not very clear why there was this media led, we would say, hysteric reaction. You also can see that still in Germany and also in some parts of Switzerland people use the term Liverpool Care Pathway without any hesitations because it was well established and people thought why to change the winning horse? I think the difference, when we looked to your country, we thought that possibly this idea of standardisation and following the rules is very strong in your country and this might really have side effects if you really follow the rules and the guidelines and possibly, at least in our country, we like rules and guidelines but we like also to adapt it individually. So there was not this fear that by giving guidance you would possibly exaggerate and put someone ‘on the pathway to hell’. I think we thought it's very black and white in your country. It's very much this idea once there is a standard approach and once there is a guideline, you need to follow it. Possibly this might be part of the problem. But it's very difficult for us to judge how strict you follow standards in your country. This is something that is difficult to know* (Professor Steffen Eychmüller, LCP 17, Switzerland)

Both Professor Eychmüller (LCP 17) in Switzerland and Professor Voltz (LCP 4) in Germany recalled robust discussions and disagreements with Professor Ellershaw about the apparent prioritisation in the UK of the ‘document’ over its underlying principles. For example, Professor Eychmüller recalled *‘many fights’* over the extent to which the document should be taken literally, recalling that once the UK withdrawal occurred, this led to some welcome freedom of interpretation and better enabled adoption of the broad framework provided by the LCP as a basis for national policy in palliative care:

*Actually I had many discussions with John and others in earlier times how literally we should take the document. I had many fights like this because I thought it cannot be that we need to make the crosses every four hours and then we guarantee the best care. So I think it's really very much about how strict the document is taken as a guarantee for good quality … So I think we had a huge discussion about how strict to follow the document and this came also together in terms of how strict translation of a document should be or could be on an international level because obviously your document from England represented the style and the attitude and the approach, how you work in your healthcare system. But if we translated it literally in our language, it was very unusual for us. So I think to discuss it on an international level actually opened the door for becoming a bit more, I would say, relaxed and to put it in a place where it is really helpful, so as a very good framework and as a very important area, that you really highlight how important this phase of life is but then to leave it to the people to make the best out of it for their use. This is what we actually did in Switzerland now* (Professor Steffen Eychmüller, LCP 17, Switzerland)

In Queensland, Australia, Associate Professor Douglas described her view of the events in the UK as a predictable ‘train wreck’ relating the unfolding disaster to a lack of emphasis on governance or overarching control of the implementation process, as well as to the key error widely reported at the time[[12]](#footnote-12) of incentivising the use of the LCP in NHS trusts in England:

*I just thought … I mean, in a way, I could almost see it was like a train wreck, because LCP was just growing all the time and everyone was taking it up. But, it just seemed like there wasn’t an overarching control of the process. I think the fact that it … there were Trusts that were paying per person that was…that went on the pathway…was appalling. I mean I think that was the undoing. I think if there had been some roll … I mean I know you can’t do it … it’s a bit like our HHSs, the Trusts are a law unto themselves. But, I think that if there were sort of overarching, sort of … I don’t know how you would do it, but that you had to have particular governances in place to use it. But that it actually had to be completely withdrawn … I mean it just flies in the face of anything we’d ever heard of here in Australia* (Associate Professor Carol Douglas, LCP 8, Queensland, Australia)

Also in Australia, Dr Mark Boughey in Victoria (LCP 12) used the term ‘*firestorm’* to describe what happened in the UK before going on to reflect that a key reason that the same events did not occur in Australia was due to the presence of quality improvement structures and associated resources, including educational resources.

In almost all cases, the withdrawal of the LCP in the UK was regarded to have had negative consequences for the mission of improving end of life care in interviewees’ countries. For example, in New Zealand it coincided and probably was a causative factor in cessation of funding for the national coordinating office for the LCP programme. Argentina was an exception insofar as there was little negative ‘fall out’. Instead the Neuberger report was used as an opportunity to try to understand what had happened in the UK. They placed emphasis on the importance of implementation, perceiving that this was missing from the Neuberger report:

… *it was mainly with us, in terms of discussing. I remember we had a meeting, ourselves, to reconsider, and of course, to read the document, because, not only the important impact, but also, what we are doing, in that sense. We knew about it, but that didn't change our minds* (Dr Gustavo de Simone, LCP 6, Argentina)

*So I was a bit angry about this report because the problem is implementation. So changes are not removed, because the cost I think for the Liverpool team, the cost of this … Also for the population, the cost of this situation with the media and this kind of discussion in the media, I think is very bad for people* (Dr Vilma Tripodoro, LCP 3, Argentina)

As alluded to above, a number of interviewees reflected on the ‘missing’ components of the LCP from their own experience of its use. A key aspect of this was the availability of specialist palliative care advice and help. In its most developed form and as described above, this realisation was communicated by Dr Costantini in Italy, following his work on the first randomised controlled trial of the LCP. He described how a trajectory of research to try to understand and explain the interaction between the specialist palliative care team and the implementation of the LCP was stopped by the international fall out from the UK withdrawal of the LCP, which occurred as the first key publications were emerging from the RCT in Italy:

*Well it’s a sad story because it was influenced by the scandal in the UK, the LCP affair. The decision to stop the LCP from your Minister of Health happened during the submission to The Lancet. The Lancet was rather severe in our conclusion of the results because The Lancet study, the phase three, was presented and left just at that and it is formally a negative trial because the P value is above 0.05, you know what it means of course. But in my opinion in the outcomes we have said we could observe a positive trend, a positive direction. I interpreted a negative trial just for the P but it was the result of six months’ hard work of the palliative care team in a ward and the results are not so big as we expected, it’s a little improvement probably but not so big. So it’s negative for the P-value greater than 0.05, and the observed improvement was not so big to justify the costs of the implementation of the LCP, in my opinion because there is an improvement but not so big. It’s not justified by the hard work of the palliative care team. I think we couldn’t find any of the UK problems because in our structured way of implementation it’s difficult to expect problems. It’s a pity because in my opinion it was a line of research that could go on but unfortunately what happened in the UK stopped any reflection, any possibility to go on in this line of research. This is an important point for me …* *What happened in the UK stopped any kind of research on the LCP and that was a problem for everybody. I would like to study which is the active component and the component not active of the LCP because there is something good and something bad in the LCP. Now it’s very difficult to do that* *(*Dr Massimo Costantini, LCP 19, Italy)

Others also came to a similar conclusion about the critical role of the specialist palliative care team, albeit from a different form of engagement with the LCP. In Denmark, Dr Otteson reflected on his experience of the work required to provide education for implementation and expressed a lack of surprise that the LCP ran into problems in the UK. He emphasised that it is essential to have specialist palliative care resource available immediately to help non specialists:

*I think education and teaching is of course necessary for implementation. But I think our experience is that there has to be a person present at least in the daytime in the department. Not a person you have to call, but a person you can get to, really getting access to information and guidance; that would be one of the major things I have thought would perhaps do something. Because if you’re working on a medical department and you have a dying patient and you should take the phone and make a call for the palliative care team there is a barrier there. So, letting the patient die without putting on a standard protocol would be much easier than calling for help … Yes, this accessibility of the competence of the experts, it should [not] be only a phone number; it should be a real person* (Dr Svend Otteson, LCP 16, Denmark)

This was a point echoed by Professor Miyashita in Japan, when he described the extent of the training challenge and the lack of availability of specialist palliative care support, which meant that a pilot project to implement the LCP into general hospital wards had to be stopped:

*…if [the] palliative care team could support them and discuss or be contacted about the LCP every day, it might have worked … And that education and support is … was very important … at that time, we stopped the pilot test at university hospitals* there (Professor Miyashita, LCP 10, Japan)

Interviewees from Norway and New Zealand offered a set of reflections about the infrastructural pre-requisites that they had come to realise were necessary to ensure the safe implementation of the LCP. In Norway, Professor Dagny Faksvåg Haugen (LCP 5) described the development of an implementation protocol involving three key people: responsible manager, physician and nurse, who all sign the registration document and are responsible for the implementation process. She expressed the belief that in addition to the safeguards provided by the latter structure, the quality of health care provision in Norway is such that many of the problems experienced in the UK would be unlikely to occur in Norway. Norway modelled its implementation protocol on arrangements in New Zealand, as our respondents there made clear:

*Yes, and the strategies that we put in place from a governance level, so we had governance over the work that we were doing and trying to keep those principles in mind. It’s probably worth pointing out as well that when you interview in Norway, Norway very much liked the way in which we had set up the national office and the coordinating and the LCP facilitators and very much copied that model very successfully to this day, I believe* (Dr Simon Allan and Bridget Marshall, LCP 2)

In most countries (except for Italy and Japan), the use of the LCP in some form continued, but the terminology used to describe the intervention had changed significantly. There was an overarching concern to avoid language used in the UK such as ‘putting patients on the pathway’. Moreover, in all cases, the term ‘LCP’ was abandoned. For example, in Austria, Dr Elisabeth Medicus (LCP 18) reported that following the withdrawal of the LCP in the UK and her careful reading of the Neuberger report, she was at pains to ensure that the term ‘LCP’ was not used (as had begun to be the case) as a shorthand to categorise patients in the last days of life. Similarly, in Norway, a revised ‘plan’ was introduced called the *‘Last Days of Life’*. Freedom from copyright obligations previously imposed by the Liverpool ‘home’ team meant that such alterations were now possible:

*But then after some years we revised our document. So at that time we made a lot of changes really. And I think that's a natural thing to do because you implement something and then you get feedback from users. And we’ve also done some studies … People have contacted us with comments. But we used all the experiences and evaluations from all the projects and studies, and made some changes to the new plan which is called the Last Days of Life. And then it was no longer a copyright document, so we were free to do that* (Professor Dagny Faksvåg Haugen. LCP 5, Norway)

Some interviewees offered some final reflections on their hopes for the future. Many continued to work with the UK Liverpool based team through new international collaborative ventures, in an effort to take forward their joint efforts to improve end of life care. We conclude with two examples here. Dr Stanley C. Macaden in India (LCP 1) reported participating in the ‘*International Collaboration for Best Care of the Dying Person’*[[13]](#footnote-13) initiated by the Liverpool team in 2014. He saw this as ‘*the LCP in its new form’*, with participation from India as an important aspect of their wider efforts to improve end of life care in India, which he describes as a *‘war’*. Similarly, Professor Voltz from Germany (LCP 4) looked forward to international collaboration with the Liverpool team, in spite of his clear criticisms of the LCP in its original form, concluding that:

*… they have to be congratulated on putting up this difficult topic of care of the dying with their endeavours, despite everything I [have] said. It's really to be congratulated there and such an important topic. Which is why it still continues being in this group as well and trying to move things in, as I see, the right direction.’* (Professor Raymond Voltz, LCP 4).

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