‘What matters to me’: A human rights approach to end of life care

End of project report

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Forward

The World Health Organisation states: “Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.” However, this does not always translate into reality, with some people and families experiencing such poor end of life care that cases end up in the courts and in some cases, public inquiries.

Understanding human rights provides practitioners with a framework for decision-making that supports them to personalise care to each individual’s unique circumstances.

Over the past three years, Sue Ryder has been delivering a training programme to empower healthcare professionals to implement a human rights-based approach to end of life care practice across the UK. This report provides evidence of the impact our training has had on participants' knowledge of human rights and their confidence to use that knowledge in practice.

Sue Ryder is delivering this training because a human rights approach to end of life care is a highly effective way to translate our values into practice. Our values are:

Supportive: We're here for people when it matters, and that includes each other. We encourage, inspire and help one another, and celebrate success.

Connected: When we work together, we can achieve so much more for the people we support. We respect that everyone at Sue Ryder plays a vital part in delivering quality care.

Impactful: We find new and inspiring ways to positively impact the people we support – from small gestures to big breakthroughs. This proactive ambition drives us forward to achieve our ambitions and transform lives.

These shared values and their associated behaviours underpin the compassion and expert care we want to be known for and enable us to deliver rights-respecting care.

If there’s one thing that’s guaranteed, it’s that we will all die, and we will die just once. In the midst of the Covid-19 pandemic, the paramount importance of rights-respecting care at the end of life has never been clearer. With that in mind, it’s incredibly important that as a society, we do all that we can to ensure the person at the end of life has the best experience possible, in challenging and changing circumstances and at a time of heightened emotion and sadness.

Educating and empowering the health and social care workforce is an important step towards delivering rights-respecting end of life care.

Sarah Gigg, Director of Nursing

If you’d like to find out more information about our work or support, visit our website at www.sueryder.org.
Executive summary

The recommendations from the Francis Report\(^1\) following the Mid-Staffordshire Public Inquiry, the controversy surrounding the generic application of the Liverpool Care Pathway,\(^2\) and poor experience of end of life care at a national level\(^3\) have highlighted the human cost of losing sight of person-centred care.

In 2016 Sue Ryder was invited by the British Institute of Human Rights (BIHR) to co-produce ‘End of Life Care and Human Rights: A Practitioner’s Guide’,\(^4\) which addresses some of the current challenges involved in ethical decision-making at the end of a person’s life.

In November 2016 Sue Ryder, funded by the Burdett Trust for Nursing, designed a training programme to support the end of life care workforce to implement the tools in the Practitioner’s Guide. The training programme was funded for three years, and data recording its scope and impact were collected for the first two years of delivery. Throughout the programme, Sue Ryder continued its collaboration with the BIHR, who quality-assured the human rights content and contributed teaching resources.

The aim of the training programme was to educate the health and social care workforce to enable the integration of human rights and the Human Rights Act, 1998\(^5\) as essential components of end of life care. The purpose of the training was to provide staff with the information needed to make objective and proportionate decisions about the provision of personalised care. The programme focused on six of the articles in the Human Rights Act, most relevant to end of life care:

- Right to Life (Article 2)
- Right to be Free from Torture, Inhuman or Degrading Treatment (Article 3)
- Right to Liberty (Article 5)
- Right to Respect for Private and Family Life, Home and Correspondence (Article 8)
- Right to Freedom of Thought, Conscience and Religion (Article 9)
- Right to Enjoy these Human Rights without Discrimination (Article 14)

The training used established case law and ‘real-life’ case studies to facilitate learning through group discussion, demonstrating the implications for practice.

There were two types of training course: a one-day training course designed for anyone working in end of life care in the health and care sectors, and a two-day ‘Train the Trainer’ course. The ‘Train the Trainer’ course was designed for educators from health and social care providers such as hospitals, hospices and care homes, to equip them with the skills to deliver the training and cascade the ‘What matters to me’ approach within their organisation and local area.

Data was collected over a two-year period of the training from 1\(^{st}\) April 2017 to 31\(^{st}\) March 2019 to assess the impact of the training on participants’ knowledge of human rights and their confidence to use their knowledge of human rights in practice. The data analysis was

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3. Leadership Alliance for the Care of Dying People, One Chance to Get it Right, 2014
based on quantitative and qualitative data collected using a questionnaire completed by participants prior to training, at 2-weeks post training and, 6-months post training.

During the 3-year funded programme, 1,970 people were trained in human rights and 113 of those completed the train the trainer course. In the 2-year data collection period 1,402 people were trained.

The data analysis was based on the responses of the 86 participants who completed questionnaires at all 3 time points.

The findings showed a positive response to the training with high levels of self-reported knowledge and confidence 2-weeks post training compared to low rates pre-training. To understand whether there was a genuine increase in knowledge levels and confidence the training needed to make a difference over a period of time. At 6-months, although there was some reduction compared to the 2-week post training levels, perceived knowledge and confidence remained high.

The 6 questions on knowledge attracted low ratings prior to the training with an average rating of 27% of participants rating their knowledge at 6 or more on a scale of 1 to 10 (1=not at all knowledgeable, 10=very knowledgeable). An exception was the question about knowledge of human rights which was rated by 40% of respondents as 6 or more. At 2-weeks post training the proportion of people rating 6 or more was on average 91%. At 6-months the average had reduced to 88%.

The 6 questions on confidence were rated low prior to training with an average rating of 23% of participants rating confidence at 6 or more on a scale of 1 to 10 (1=not at all confident, 10=very confident). At 2-weeks post training the proportion of participants rating 6 or more was on average 94%. At 6-months the average had reduced to 86%.

At 6-months reported knowledge and confidence remained high although both showed some reduction. The findings showed more of a reduction in confidence than knowledge when compared with responses 2-weeks post training.

Maintaining knowledge and confidence over time was identified as a barrier to implementing human rights in the workplace. Retention of the volume of information, having a full understanding of the legislation and keeping up to date with changes in the law from the training may be a reason for the reduction in scores over time.

Comments highlighted further support that would help to maintain the knowledge over time including an e-learning package, regular updates on changes in legislation and ongoing refresher training.

To ensure a wider understanding across all teams it was felt that human rights training should be mandatory for all staff. Human rights principles are not only relevant to people providing ‘front line’ care i.e. medical and nursing staff but should be considered by staff in all roles and embedded throughout the organisation.

Further barriers to implementing human rights in the workplace were identified. These included traditional ways of working where there is a feeling that health professionals ‘know what is best’ for service users. This requires a change in culture and although the training
programme has a role to play in breaking down barriers by raising awareness of the need to respect service users’ views, it cannot by itself change the culture.

The training programme helps staff to understand the rights of individuals and to recognise situations involving human rights however, in practice it may not always be possible to enact the choices of individuals, when outweighed by the rights of others. Balancing the, sometimes, conflicting needs of service users and families was an area participants felt less confident with and may be an area for further training.

Another theme was the challenges of providers enacting service users’ personal preferences with limited resources in the health and social care sector. Conflict arose when it was not possible to offer the care options required to meet the expectations of service users. Enacting people’s personal preferences has to be considered in context of the resources available. The training cannot change this but where the programme can help is in giving staff the confidence to assess situations using a human rights approach, and explain to service users and families what options are realistically available to them.

Although there are barriers to implementing a human rights approach, training plays a part in breaking them down. To extend the training to create greater awareness it is necessary to have the capacity across organisations to do this. There were fewer applicants for the train the trainer course than anticipated. Based on responses from the questionnaires, the volume of knowledge required to train others may have been a factor in this, particularly when added to existing workloads. Respondents felt that continuing support was important to enable trainers to maintain their knowledge and confidence.

Although not all respondents had implemented change in the 6 months following the training they did report an increased awareness of how human rights reinforces and enables personalised care and an increased confidence in identifying and raising human rights issues. Many had shared resources with colleagues in their workplace and across organisations. The principles and the learning had been incorporated into in-house training courses and policies. In one particular example the human rights language was reported to be helpful in supporting the rights of a service user who wanted to be cared for at home when a healthcare professional felt it was inappropriate.

Sustaining the learning and embedding human rights needs to be an ongoing process. Training needs to be available to the wider workforce along with refresher courses to maintain knowledge and confidence.

Further research on the impact of human rights training would be beneficial in understanding the barriers to implementing this approach and to learn from examples of best practice in the workplace.

Recommendations

- Widen the reach of the programme through an online platform to deliver more training to empower more staff across diverse health and social care providers throughout the UK
- Evaluate the impact of the training on practice and the impact on service users’ experience of rights-respecting care.
- Develop additional learning resources including short-form materials such as posters and bespoke resources for specific conditions and cases.
1. Introduction

1.1 Purpose of the report

In 2017 Sue Ryder developed and implemented a training programme on Human Rights at the end of life with the support of the British Institute of Human Rights (BIHR). The programme, ‘What Matters to Me’ (WMTM) was funded for a 3 year period.

This report represents an analysis of the data collected during the training delivered over the two-year period from 1st April 2017 to 31st March 2019. During this time 1,402 people participated exceeding the target of 810. Only those who attended a Sue Ryder led training workshop during this period were included. Those who attended training delivered by others, or followed the train the trainer course, were excluded.

The report is examines the data to determine whether the WMTM training improved the knowledge of human rights and the confidence to use it in practice, of staff working with service users at the end of life. It also presents information concerning increases in knowledge and confidence and the extent to which these were sustained once staff returned to the workplace.

The impact of the training was measured at 2-weeks post training against pre-training baseline rates with sustainability measured at 6-months post training against the rates reported at 2-weeks. Participants’ self-reported assessment of their knowledge and confidence were measured.

1.2 Context

In 2016, the End of Life Care Coalition\(^6\) estimated that 48,000 people in England experienced poor care in the last 3 months of their life. Despite the recommendations of the Francis Report,\(^1\) following the Mid-Staffordshire Public Inquiry and the controversy surrounding the generic application of the Liverpool Care Pathway\(^7\) and its subsequent withdrawal\(^8\), complaints about poor end of life care have not been eliminated\(^9\). As a result, there is a need to explore other approaches to improve experience at end of life, one of which is the consideration of Human Rights.

The UK Human Rights Act, 1998\(^5\) underpins all UK legislation e.g. the Mental Capacity Act, 2005\(^10\) and its associated Deprivation of Liberty Safeguards. Using the Human Rights Act as a framework for decision-making may help ensure that the best possible decisions are made, in that they are objective and proportionate, for each individual.

1.3 Sue Ryder and British Institute of Human Rights (BIHR)

Sue Ryder was invited to work with the BIHR to co-produce a practical guide entitled ‘End of Life Care and Human Rights: A Practitioner’s Guide’, which was published in May 2016\(^11\) (https://www.sueryder.org/for-healthcare-professionals/education-and-training/human-rights-)

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\(^7\) Department of Health, *More Care, Less Pathway: a review of the Liverpool Care Pathway*, 2013

\(^8\) Leadership Alliance for the Care of Dying People, *One Chance to Get it Right*, 2014

\(^9\) Parliamentary and Health Services Ombudsman, *Dying without Dignity*, 2014/15


end-of-life-care/download). The guide provides practical tools to aid professionals’ ethical and legal decision-making in care provision at the end of a person’s life. The learning from the problems encountered with the introduction of the Liverpool Care Pathway showed that a tool to improve practice will not have a positive impact unless the care workforce have the education and training to use it.\(^\text{12}\)

Sue Ryder continued its collaboration with BIHR, who quality assured the human rights content of the training and contributed teaching resources.

### 1.4 Burdett Trust for Nursing

Sue Ryder secured a grant from the Burdett Trust for Nursing, to create and deliver a three-year training programme offered free of charge in the UK. The aim of the programme was to help empower health and social care staff, working in end of life care, to implement the tools set out in the Practitioner’s Guide.

Over the 3 years the programme was expected to:

- Deliver 120 courses
- Train 1350 staff
- Train 360 trainers

### 1.5 ‘What matters to me’: a human rights approach to end of life care

Whilst the content was quality assured by Sue Ryder and the BIHR, Sue Ryder delivered the training which was designed to educate and thus empower the health and social care workforce to use human rights as a framework to underpin ethical decision-making and support the delivery of personalised care for service users at the end of life.

The programme focused on six of the articles in the Human Rights Act, 1998\(^5\) most relevant to end of life care:

- Right to Life (Article 2)
- Right to be Free from Torture, Inhuman or Degrading Treatment (Article 3)
- Right to Liberty (Article 5)
- Right to Respect for Private and Family Life, Home and Correspondence (Article 8)
- Right to Freedom of Thought, Conscience and Religion (Article 9)
- Right to Enjoy these Human Rights without Discrimination (Article 14)

Training courses were free and held at the 7 Sue Ryder hospices and 4 neurological care centres in England and Scotland, and were open to both Sue Ryder staff and those employed by external health and social care organisations. Sue Ryder also delivered free training courses, on request, for external organisations.

#### 1.5.1 Programme structure

\(^{12}\) Department of Health, More Care, Less Pathway: a review of the Liverpool Care Pathway, 2013
At the outset of the programme, 3 training courses were available in the UK:

- Half-day for the non-registered workforce (4 hours)
- 1 day for the registered workforce (6 hours)
- 2-day train the trainer (12 hours)

In Scotland, a half-day, rather than a full-day course was offered at Sue Ryder’s Neurological Care Centre in Aberdeen. This was a pragmatic decision to allow for the longer travel distances of those attending. The core content of the course did not differ from the full-day but the approach was simplified with fewer examples of case law used. All training delivered was adapted for Scotland, Northern Ireland and Wales, to accommodate differences in language, policy, laws and health and social care systems.

The 2-day ‘Train the Trainer’ course was made available to participants who had completed the one-day training, and had responsibility for the education and training of others as part of their day-to-day role. Once completed, new trainers were given an unlimited licence to use all the resources and materials developed in order to deliver training to health and social care staff in their locality. Training materials can be adapted to best suit local need. Training provided by these trainers was not delivered on behalf of Sue Ryder or the BIHR and the quality of their delivery was not monitored and is not included in this report.

The half-day course for non-registered staff was discontinued from January 2019 in response to the low number of staff attending. It was also decided that multidisciplinary training would be more beneficial to reflect the way teams operate in the workplace. The content was the same for both groups but the full-day course included more examples and discussion of case law.

The format, content and delivery of each individual training workshop were evaluated using a course questionnaire, completed by each participant at the end of the session. Results were monitored by the ‘What Matters to Me’ steering group, and changes made to the format and content of the training as required. The feedback was consistently positive and changes were minor, primarily involving updates to content where new case law examples had arisen.

1.5.2 Programme delivery

The programme delivered over the three year funded period involved:

- 172 workshops (target 120) – 57 hosted by external organisations but delivered by Sue Ryder
- 1970 staff trained (target 1350) – 1191 were from external organisations
- 113 trainers trained (target 360)

The programme exceeded the targets for the delivery of workshops and staff trained but did not meet the target for the number of trainers trained. Fewer participants than anticipated applied for the Train Trainer programme. The possible reasons for this are explored in the summary.

1.5.3 Geographical reach
Over the 3 year funded period, Sue Ryder delivered WMTM across the UK enabling wider access to local training. Map A shows the locations where courses were delivered and Map B the locations for those people who attended the Train the Trainer course and are now able to expand the training offer.

**Figure 1: Location of courses delivered**

**Figure 2: Location of trainers**

2. **Methodology**

Sue Ryder used the Health Regulatory Authority’s (HRA) decision-making tool (http://www.hra-decisiontools.org.uk/ethics/) to ascertain whether this would be classified as research or service evaluation. The HRA tool indicated this would be classified as a service evaluation. The Sue Ryder Research Governance Group also reviewed and approved the methodology, and because it was classified as service evaluation formal ethical approval was not required. For those taking part, consent was implied by self-completion and submission of the questionnaire.

To measure whether the WMTM training improved the knowledge of human rights and the confidence to use it in practice and whether it was sustained over a period of time, a quantitative approach was taken. Qualitative data was also collected in the form of free-text responses to questions about the barriers to implementing human rights in the workplace, changes made to practice as a result of training, and any other general comments.

The impact of the training was defined as a change over time in participants’ self-reported rates against a set of questions relating to knowledge and confidence in using human rights in practice (see Appendices). To measure this, a ‘before and after’ approach was adopted comparing self-reported rates from baseline data, collected prior to the training, to data collected shortly after training (at 2-weeks). This data indicated the immediate effect of the
training with the longer-term effect demonstrated by the data collected at a point when participants had the opportunity to implement the learning in the workplace (at 6-months).

A questionnaire was designed to capture the self-reported scores at the 3 time points (pre, 2-week post, 6-month post). A questionnaire was felt to be an appropriate tool to collect data in order to reach the number of people anticipated to attend the training who were geographically dispersed. The target for the number to be trained over the 2 years was agreed with the Burdett Trust for Nursing at 810 so there was a likelihood that the number of completed questionnaires submitted during the 2-year data collection period could be high as all participants were invited to take part. The questionnaire was adapted from a similar evaluation commissioned by the Scottish Human Rights Commission in 2011.\textsuperscript{13} The Scottish evaluation\textsuperscript{15} was published but it is not known whether the tool was validated prior to its use.

The questions on knowledge and confidence invited respondents to rate their knowledge/confidence on a scale of 1 to 10, with 1 being not at all knowledgeable or confident and 10 being very knowledgeable or confident.

Additionally four questions were included about whether the participants felt the training had helped them in their practice to:

- Resolve conflicts between the needs of different service users
- Improve the way that service users, their families and carers are involved in decision-making
- Deliver better person-centred care
- Balance risk in decision-making

For the additional four questions, response categories were Yes, Maybe, No, Not Applicable. The metrics used were replicated from those used in the Scottish Human Rights Commission evaluation\textsuperscript{15}.

It was acknowledged that collecting self-reported scores meant the results were subjective but this was considered to be useful method of collecting participants’ personal experience from a large cohort.

The questionnaire was developed to be completed online for ease of distribution (via a web link) and so that all responses could be collated directly into a database for analysis. It was acknowledged that the response rate for an online questionnaire could be low but this was balanced against the ease of distribution and the resources available for collection. Securing access to a computer to complete a questionnaire online was not considered to be problematic as participants had to apply for training places through an online booking system.

The report was based on the number of participants attending the training between 1st April 2017 up to and including 31st March 2019 which is a 2 year data collection period out of the 3 year project. The final 6-month questionnaire was sent out in September 2019. This allowed for all data to be received and analysed by the end of the three year project, with no further data received after 31st October 2019. The majority of training courses were delivered during this 2-year period attended by 1,402 participants (1,970 in 3-years).

\textsuperscript{13}Scottish Human Rights Commission, \textit{Evaluation of Care About Rights}, GEN, The University of Bedfordshire and Queen Margaret University, October 2011
Applicants were sent a web link to an online questionnaire prior to attending the training to establish a baseline of their knowledge of human rights and their confidence in using them in practice. Following the training the web link was emailed to participants at 2-weeks and then again at 6-months, asking participants to complete the questionnaire again to measure any change in their rating of their knowledge and confidence.

**Of the 1,402 participants who attended training, 86 participants completed all 3 questionnaires.**

In order to download their course certificate the participants were required complete the 2-week questionnaire online. This increased the number of responses, however no such requirement or incentive applied for the 6-month questionnaire and reminders were not sent. In the remainder of the report the focus is on the responses of the 86 participants who completed questionnaires at all three time points.

2.1 **Analysis**

All three sets of responses to the questionnaires (pre, 2-week, and 6-month) were collated in a database and matched to individuals using their name and date of training attended. These were then coded to anonymise the data for analysis. The responses were compared over time for each participant with the ‘before and after’ effect of the training based on their self-ratings. Data was aggregated and comparisons made between those that rated themselves between 6 and 10 on the scale prior to training and at the two time points post training. The aim was to measure the proportion of participants who rated themselves at the higher end of the scale post training.

Qualitative data was analysed by reviewing the free-text responses and identifying common themes as they emerged from the questions on barriers to implementation, impact on practice and general comments. A manual review of free-text responses was carried out.

3. **Results**

The analysis of the data focuses on the results from the 86 participants who completed all three questionnaires.

**Figure 3: Roles of participants**

The roles of the participants are shown in figure3. Nurses were the largest proportion (59%) of participants.

The ‘other’ category included those who identified themselves as managers, ward clerks, paramedic, head of spiritual care and safeguarding lead.
3.1 Results on knowledge

The charts below show the percentage of participants rating their knowledge between 6 and 10 on the scale before and after the training, at 2 weeks and then at 6 months.

The results show that the training increased participants’ self-reported levels of knowledge of human rights compared to the baseline. At 6-months the rating of knowledge was sustained with a high proportion still rating themselves between 6 and 10 even though a number of participants did rate their individual score one or more points lower than at 2-weeks. On average for overall ‘knowledge’ questions, 40% of participants gave a lower score than at 2-weeks with 33% giving the same score and 27% a higher score. (see below for number of participants scoring lower, the same and higher for each question).

**Rating: 1 = ‘not at all knowledgeable’ and 10 = ‘very knowledgeable’**

**Chart 1: How would you rate your knowledge and understanding of human rights?**

At 2-weeks post training 94% of participants rated their knowledge and understanding of human rights between 6 and 10 on the scale, an increase from 40% pre-training. At 6-months, 91% of participants still rated their knowledge between 6 and 10.

Overall at 6 months, 56% of participants maintained or improved their rate compared to that at 2-weeks and although 44% reported a lower rate than previously, the majority (87%) remained at 6 or above. Of the participants who gave a score at 6-months: 38 rated it lower, 27 rated it the same and 21 rated it higher than at 2-weeks (86 responses).

**Chart 2: How would you rate your knowledge about the relationship between human rights and other legislation?**

At 2-weeks post training 91% of participants rated their knowledge about the relationship between human rights and other legislation between 6 and 10 on the scale, an increase from 23% pre-training. At 6-months, 88% of participants rated their knowledge between 6 and 10.

Overall at 6 months, 64% of participants maintained or improved their rate compared to that at 2-weeks and although 36% reported a lower rate than previously, a high proportion (71%) remained at 6 or above. Of the participants who gave a score at 6-months: 31 rated it lower, 27 rated it the same and 28 rated it higher than at 2-weeks (86 responses).
Chart 3: How would you rate your knowledge about the relationship between human rights and the national End of Life Care Strategy and Policy?

At 2-weeks post training 92% of participants rated their knowledge about the relationship between human rights and the national end of life care strategy and policy between 6 and 10 on the scale, an increase from 28% pre-training. At 6-months, 85% of participants still rated their knowledge between 6 and 10.

Overall at 6 months, 62% of participants maintained or improved their rate compared to that at 2-weeks and although 38% reported a lower rate than previously, a high proportion (76%) remained at 6 or above. Of the participants who gave a score at 6-months: 33 rated it lower, 32 rated it the same and 21 rated it higher than at 2-weeks (86 responses).

Chart 4: How would you rate your knowledge of the UK Human Rights Act?

At 2-weeks post training 93% of participants rated their knowledge of the UK Human Rights Act between 6 and 10 on the scale, an increase from 27% pre-training. At 6-months, 91% of participants still rated their knowledge between 6 and 10.

Overall at 6 months, 57% of participants maintained or improved their rate compared to that at 2-weeks and although 43% reported a lower rate than previously, the majority (85%) remained at 6 or above. Of the participants who gave a score at 6-months: 34 rated it lower, 25 rated it the same and 21 rated it higher than at 2-weeks (80 responses).

Chart 5: How would you rate your knowledge of the Universal Declaration of Human Rights?

At 2-weeks post training 88% of participants rated their knowledge of the Universal Declaration of Human Rights between 6 and 10 on the scale, an increase from 23% pre-training. At 6-months, 85% of participants still rated their knowledge between 6 and 10.

Overall at 6 months, 60% of participants maintained or improved their rate compared to that at 2-weeks and although 40% reported a lower rate than previously, a high proportion (69%) remained at 6 or above. Of the participants who gave a score at 6-months: 32 rated it lower, 27 rated it the same and 22 rated it higher than at 2-weeks (81 responses).
At 2-weeks post training 86% of participants rated their knowledge of the European Convention of Human Rights links with the Human Rights Act between 6 and 10 on the scale, an increase from 21% pre-training. At 6-months, 85% of participants still rated their knowledge between 6 and 10.

Overall at 6 months, 58% of participants maintained or improved their rate compared to that at 2-weeks and although 42% reported a lower rate than previously, a high proportion (73%) remained at 6 or above. Of the participants who gave a score at 6-months: 33 rated it lower, 24 rated it the same and 22 rated it higher than at 2-weeks (79 responses).

### 3.2 Results on confidence

The charts below show the percentage of participants rating their confidence between 6 and 10 (above average) on the scale before and after the training, at 2 weeks and 6 months. Also shown is the percentage of participants who reported a lower score at 6 months than at 2 weeks although a high proportion still reported a rate of 6 or more (above average).

The results show that the training increased participants’ self-reported level of confidence to implement a human rights approach in practice compared to the baseline. At 6-months the confidence was sustained with a high proportion still rating themselves between 6 and 10 even though a number of participants did rate their confidence lower than at 2-weeks. On average for overall ‘confidence’ questions, 40% of participants gave a lower score than at 2-weeks with 31% giving the same score and 29% a higher score. (see below for number of participants scoring lower, the same and higher for each question).

**Rating: 1 = ‘not at all confident’ and 10 = ‘very confident’**

At 2-weeks post training 93% of participants rated their confidence in explaining human rights to colleagues between 6 and 10 on the scale, an increase from 22% pre-training. At 6-months, 85% of participants still rated their confidence between 6 and 10.

Overall at 6 months, 64% of participants maintained or improved their rate compared to that at 2-weeks and although 36% reported a lower rate than previously, a high proportion (65%)
remained at 6 or above. Of the participants who gave a score at 6-months: 31 rated it lower, 28 rated it the same and 27 rated it higher than at 2-weeks (86 responses).

Chart 8: How confident do you feel in explaining human rights to service users?

At 2-weeks post training 92% of participants rated their confidence in explaining human rights to service users between 6 and 10 on the scale, an increase from 21% pre-training. At 6-months, 84% of participants still rated their confidence between 6 and 10. Overall at 6 months, 64% of participants maintained or improved their rate compared to that at 2-weeks and although 36% reported a lower rate than previously, a high proportion (65%) remained at 6 or above. Of the participants who gave a score at 6-months: 31 rated it lower, 27 rated it the same and 28 rated it higher than at 2-weeks (86 responses).

Chart 9: How confident are you to use human rights as a way to enable shared decision-making at end of life care?

At 2-weeks post training 95% of participants rated their confidence to use human rights as a way to enable shared decision-making at end of life care between 6 and 10 on the scale, an increase from 26% pre-training. At 6-months, 88% of participants still rated their confidence between 6 and 10. Overall at 6 months, 57% of participants maintained or improved their rate compared to that at 2-weeks and although 43% reported a lower rate than previously, a high proportion (78%) remained at 6 or above. Of the participants who gave a score at 6-months: 37 rated it lower, 26 rated it the same and 23 rated it higher than at 2-weeks (86 responses).

Chart 10: How confident are you to use human rights to enable those in your care to make decisions at end of life?

At 2-weeks post training 97% of participants rated their confidence to use human rights to enable those in their care to make decisions at end of life between 6 and 10 on the scale, an increase from 27% pre-training. At 6-months, 85% of participants still rated their confidence between 6 and 10.
Overall at 6 months, 56% of participants maintained or improved their rate compared to that at 2-weeks and although 44% reported a lower rate than previously, a high proportion (71%) remained at 6 or above. Of the participants who gave a score at 6-months: 38 rated it lower, 26 rated it the same and 22 rated it higher than at 2-weeks (86 responses).

**Chart 11: How confident are you to use human rights to resolve conflicts between the needs of service users?**

At 2-weeks post training 94% of participants rated their confidence to use human rights to resolve conflicts between needs of service users between 6 and 10 on the scale, an increase from 23% pre-training. At 6-months, 87% of participants still rated their confidence between 6 and 10. Overall at 6 months, 57% of participants maintained or improved their rate compared to that at 2-weeks and although 43% reported a lower rate than previously, a high proportion (73%) remained at 6 or above. Of the participants who gave a score at 6-months: 37 rated it lower, 27 rated it the same and 22 rated it higher than at 2-weeks 86 responses).

**Chart 12: How confident do you feel in documenting decisions using the human rights articles?**

At 2-weeks post training 91% of participants rated their confidence in documenting decisions using the human rights articles between 6 and 10 on the scale, an increase from 20% pre-training. At 6-months, 85% of participants still rated their confidence between 6 and 10. Overall at 6 months, 62% of participants maintained or improved their rate compared to that at 2-weeks and although 38% reported a lower rate than previously, a high proportion (64%) remained at 6 or above. Of the participants who gave a score at 6-months: 33 rated it lower, 24 rated it the same and 29 rated it higher than at 2-weeks 86 responses).

### 3.3 Results for impact on practice

An additional four questions were included in the two post-training questionnaires (at 2-weeks and 6-months) to identify whether the training had helped participants in their practice to:

- Resolve conflicts between the needs of different service users
- Improve the way that service users, their families and carers are involved in decision-making.
- Deliver better person-centred care.
- Balance risk in decision-making.
At 2-weeks following training 50% of participants reported that the training helped them to resolve conflicts between the needs of different service users. After 6 months, 44% responded that it had helped.

At 2-weeks following training 77% of participants reported that the training helped them to improve the way that service users, their families and carers are involved in decision-making. After 6 months, 67% responded that it had helped.

At 2-weeks following training 78% of participants reported that the training helped them to deliver better person-centred care. After 6 months, 70% responded that it had helped.

At 2-weeks following training 74% of participants reported that the training helped them to balance risk in decision-making. After 6 months, 69% responded that it had helped.

Although the proportion of participants responding ‘Yes’ to each question reduced slightly from the initial response 2-weeks after training, the majority of other responses were ‘Maybe’ rather than ‘No’.

Interestingly there were responses of ‘not applicable’ to the four questions relating to how the training supported practice. On review, these comments were made by participants who may not have been directly involved in providing care (facilities manager, ward clerk, education lead and pastoral care worker). The human rights principles are relevant to all roles in health and social care so in the future measuring the impact on non-clinical work may be an area to explore.

The free-text comments indicated that for some participants a response of ‘Maybe’ was because they felt they were already doing this in practice and so it was not a result of the training.
“I would hope that with my level of experience I have been adhering to the four previous points already - as many of my clinical colleagues have already voiced. I am not sure whether attending the human rights training has actually improved my practice in these areas. I do think that this training would be really useful delivered to pre-registration nursing students / nursing associates and medical students”. Practice Educator

“It was a very good course. Useful to understand the legislation better and apply to real clinical scenarios. In reality this holistic way of approaching looking after patients is what good palliative care teams already do”. Doctor

The reasons for the reduction of those responding ‘yes’ at 6-months are not known but as there were reports of barriers to implementing the learning in practice these may have contributed.

3.4 Barriers to implementing Human Rights in the workplace

There were common themes in the responses to the questions about the barriers to implementing human rights in the workplace. These were:

- Lack of knowledge, understanding and awareness of human rights within the multi-disciplinary team (MDT)
- Lack of knowledge, understanding and awareness of human rights by service users and their families
- Ways of working
- Resources – staffing, finances and time
- Maintaining knowledge and confidence over time

The lack of awareness, knowledge and understanding, particularly of the legislation, among the MDT was identified as a barrier to implementing a human rights based approach to care in the workplace. This became more complex when working across multiple agencies with differing policies and procedures. The interpretation of human rights law by different professionals was raised as an issue highlighting the need for teams to have a shared understanding of human rights and opportunities to discuss differences in approach. It is recognised that not all cases involving human rights have a clear answer but it was felt by participants that all staff having the same training would help.

Lack of knowledge, understanding and awareness on the part of service users or their families meant that often relatives spoke on behalf of the service user rather than the service user expressing their own wishes. This may be done with good intentions based on a belief that they ‘know what’s best’ for the person concerned. In situations where a service user may be too ill to be part of the decision-making or has limited capacity or communication difficulties it may be necessary for decisions to be made by families but where the service user is able to express their own views these must have priority. Raising awareness of human rights with families was considered important to ensure that service users had an opportunity to make their wishes known although it was acknowledged that in some cases there could be conflict when trying to respect the human rights of both parties. An example given was where a service user wanted to be cared for at home but the family struggled to cope with this. This scenario demonstrates the complexity of the subject and the difficulties in meeting the Right to Respect for Private and Family Life, Home and Correspondence of
the service user where the decision may infringe the Right to Respect for Private and Family Life, Home and Correspondence of the family.

“Relatives expectations wants and wishes can over shadow the individual patients’ wishes, and individuals may feel obliged to ‘conform’ to peer pressure”. Nurse

“I think the main barriers are relatives/next of kin doing what they think is right and not looking at what’s best for the person (working in that persons best interest)”. Nurse

Ways of working, particularly the medical model in the healthcare sector was mentioned as a barrier to implementing human rights in the workplace. This led to staff making assumptions, from a clinical point of view, on ‘what is best’ for service users rather than considering the person’s autonomy to make their own decisions -.

“We work in a predominantly medical model and as a result, professionals can take a paternalistic stand point which at times can be risk averse and overly protective. As a result, the voice of the person and their rights as an individual are not always heard/considered”. Educator/Researcher

Lack of resources, for example staffing levels and finance, were mentioned as barriers to exercising real choice. Financial constraints can have an impact on the realistic options available for the delivery of care so even if service users choose to be cared for at home, packages of care may not be available to enable this. Resources can be lawfully restricted under Article 8, the Right to Respect for Private and Family Life, Home and Correspondence. Limited facilities at some providers mean that only shared bedrooms or shared bathrooms are available constraining the ability to respect their Right to Respect for Private and Family Life, Home and Correspondence. Time pressures on staff may limit their ability to get to know service users and their wishes, restricting their ability to explore all options for those they are caring for. Time pressures and staff shortages often led to staff being unable to be released from their work to attend training on human rights resulting in a barrier to further implementation in the workplace.

“Conflicting priorities in that often giving people choice = money/resources. I feel that good practice is compromised through a lack of resources”. Nurse

“Time restrictions in palliative care sometimes mean all avenues cannot be explored”. Nurse

“The main barrier I find is the pressure of time as discussing with clients/staff re human rights takes longer as find need to explain about human rights as well as the wishes of the person”. Nurse

Conflicts can occur when it is not possible to fulfil the personal preferences of service users at end of life. This can be due to limited facilities or care options, as outlined above, but also if a person’s medical needs dictate the place of care, for example, if they need a hospital intervention. Conflict between the rights of service users and the rights of their families can arise creating a situation where it is not possible to respect the wishes of everyone involved. For example, if the family want the service user to return home for care (Right to Respect for Private and Family Life, Home and Correspondence) but the care required by the service user can only be delivered in a hospital setting because of the resources available, (to ensure that the service user’s Right to Life and Right to be Free from Inhuman or Degrading
Treatment is respected and protected, staff are in a position of seeking to balance the rights of both parties.

“Safeguarding situations can be complex as there are often ethical dilemmas with regard to not being able to respect the rights of all of the people involved I find these situations very difficult to work with...” Social Worker

Maintaining knowledge and confidence over time was a barrier to the implementation of HR due to the volume of information and the complexity of the subject. Concerns about the need to keep up to date with changes in legislation, retention of information and its dissemination to colleagues post training, were raised. For those who had completed the train the trainer programme worries were expressed that they were not ‘experts’ in human rights and may be providing training to colleagues who knew more about the subject than they did themselves. This affected their confidence as they did not want to ‘insult their expertise’. Another person reported not wanting to ‘rock the boat’ indicating a lack of confidence in challenging other peoples’ behaviour whether service users, families or colleagues.

“I did the course way back in March. It is very difficult to retain all the facts that I was taught all those months ago when I did the course, especially all the laws and legislation of Human Rights. My aim is to always try to care for people in the same way that I would like to be cared for myself, with respect, compassion, understanding and dignity...” Nurse

To address the difficulties in maintaining knowledge and confidence over time a number of respondents suggested solutions which included refresher courses either face to face or as an e-learning package. Other quick reference aids were suggested including a poster of the Human Rights Act and a one page summary of the guide with regular updates on changes in legislation.

“Update/refresher - was really empowered in session but realise I have forgotten a lot”. Allied Health Professional

The analysis of the data identified a number of themes concerning barriers to implementing the learning in the workplace, however not everyone experienced barriers.

“So far there have not been barriers to implementing a human rights approach, although there have been some challenging discussions”. Clinical Skills Facilitator

3.5 Putting the learning into practice

Participants were asked to list three things they had done differently in their practice since completing the training. These are grouped into 3 key themes:

1. Sharing the learning
2. Confidence to use human rights
3. Embedding human rights for better personalised care

Respondents reported feeling confident to identify a human rights issue, to raise it, and to challenge colleagues and question decisions if they felt they were not respecting or protecting service users’ human rights, when dealing with family conflicts and contributing to safeguarding meetings.
One example of confidence to use human rights was given by a participant regarding a service user who had wanted to remain at home despite a recommendation from a healthcare professional that this was not appropriate because the house was dirty and unsuitable for the service user. The participant felt able to support the service user in this decision using human rights language to argue the service user had mental capacity to understand the risks involved.

Other participants shared what they had learned with colleagues in their workplace. They had explained the human rights approach and this helped ensure service users’ wishes were recorded accurately in documentation. In some cases, the human rights training had been used to argue for the need for Advance Care Planning (ACP) with other agencies such as Care Homes and with GPs to facilitate personalised care.

Respondents shared resources such as the Human Rights Act poster and the Practitioner’s Guide to promote awareness, encouraging other members of the team to consider the human rights of the person being cared for.

“I have shared the human rights information to partners as a method for introducing models of engagement” Engagement Lead

“Since the training I have been much more aware of the rights of individuals and have found that using Human Rights based language is a helpful way of challenging other members of the team when they might be being over protective/risk averse”. Educator/ Researcher

Not all respondents had changed their practice within the 6 months but did report an increased awareness of how human rights reinforces and enables personalised care. Staff had a greater understanding of how a service user’s personal preferences and choices at end of life should be at the core of all decisions.

Staff in education and management roles made changes to their own training programmes including induction training for staff to incorporate and embed human rights in practice. Others had integrated some of the material into training sessions with student social workers and incorporated reference to the Human Rights Act in a policy on nutrition and hydration at end of life.

“I changed some in house training courses to incorporate human rights more effectively” Quality Manager

“The training was very thought provoking and helpful. I love the Practitioner’s Guide! All the information gleaned from events such as this one helps me in my mission to make EoL care better. I am currently focused on trying to embed ACP [Advanced Care Planning] as normal procedure on entry to Care Homes and with regular scheduled and PRN reviews”. Nurse

[PRN – ‘pro re nata’- ‘just in time medication’]

4. Discussion

The aim of the WMTM training was to educate the health and social care workforce, to increase knowledge of human rights and confidence to ensure adherence to the Human Rights Act in the provision of end of life care.
The data record the achievement of this aim in the increases in participants’ self-reported rating of knowledge and confidence at 2-weeks post training and again at 6 months. The relatively low number of responses to all 3 questionnaires limits the generalisability of the findings however they do provide an indication of self-rated knowledge and confidence of 86 participants and a baseline for further research.

The findings show a positive response to the training with high levels of self-reported knowledge and confidence at 2-weeks following the training compared to low rates pre-training. This is perhaps unsurprising as the information and group discussions would still be fresh in participants’ minds at that point in time.

At 6-months post training, high levels of knowledge and confidence were maintained with only a small reduction in the overall percentage compared to that at 2-weeks. Some reduction over time is not unexpected, particularly if participants had not put the learning into practice as soon as they had returned to the workplace. Retaining large volumes of information becomes more difficult over time without some form of refresher training. This was a barrier mentioned by some of the respondents in the follow-up questionnaires.

The free text responses indicate that implementing human rights in the workplace is complex. In addition to difficulties experienced with maintaining knowledge and keeping up to date with changes in legislation, there were barriers relating to traditional ways of working and maintaining service users’ human rights within available resources.

The training was successful in increasing the reported knowledge and confidence of those taking part, but implementing human rights in practice is a culture change requiring different ways of working. A theme in the data analysis was that the culture in healthcare was often seen as a barrier to implementing human rights through the “paternalistic view that health professionals ‘know best’”. The WMTM training programme has a role to play in breaking down barriers by raising awareness of the need to respect service users' views but it cannot necessarily change the culture. If more people undertake the training and the awareness of human rights increases across multi-disciplinary teams it may help to encourage future culture changes.

The training helps staff to understand the rights of individuals and to recognise situations involving human rights however in practice it may not always be possible to respect the choices of individuals. There may be conflicting needs between service users where one person’s choices may infringe on another person’s rights. Balancing these needs can present problems and the data analysis demonstrated that this is an area participants were less confident with. Situations where this occurs can be complex, particularly where safeguarding is involved, so this could be a topic where further training may be beneficial.

Another theme was that finite resources in the health and social care sector limit the capacity of providers to respect service users’ personal preferences. Staff can experience conflict when it is not possible to offer the care options required to meet preferences, for example, when the service user wishes to go home to die but the resources are not available to care for them safely at home. The training cannot change offset the impact of limited resources but it can help give staff the confidence to assess situations, to support service users and families to take positive risks where resources may not be available. Increased knowledge and confidence also enable staff to challenge funders if resource allocation decisions are not
the result of a fair transparent process or one which does not meet the three-stage test, set out in the Human Rights Act, for any decision to be lawful, legitimate and proportionate.

Although there are barriers to implementing a human rights approach, training plays a part in breaking these down. To extend the training to create greater awareness it is necessary to have the capacity across organisations to do this. The train the trainer course was designed to equip others to implement the training programme in their own workplace.

Train the trainer courses were attended by 113 people enabling the knowledge to be embedded further, however the number of applications for the course was lower than 360 target agreed with the Burdett Trust for Nursing for funding. The data analysis identified some reasons for this, including the lack of capacity to be released from practice to undergo a further two days training, despite being free and the lack of capacity to deliver more training on top of what they were already delivering. Once trained, some trainers did not go on to deliver training in their workplace, with comments about a lack of confidence due to ‘not being an expert’ or concerns about the volume of information and the need to keep up to date with legislation. People who attended the training were already responsible for delivering a number of mandatory courses and felt somewhat overwhelmed about adding to their workload, particularly with a course that requires constant updating to remain relevant.

In response to concerns raised by trainers, the Sue Ryder Human Rights Lead established an online Community of Practice. This cloud-based workspace is hosted external to Sue Ryder and is for all trainers who undertook the train the trainer course regardless of where they work. Those who join the Community of Practice are able to download training materials, access updates on case law and policies relating to human rights and access a chatroom facility for professional support and development. It is hoped that through this facility trainers can feel supported to deliver the human rights training throughout their organisations.

Additionally, Sue Ryder has made human rights training a mandatory course for its hospice and neurological care centre staff and has introduced an e-learning refresher module to enable staff to maintain their knowledge in this area. A human rights conference was held last year and another is planned for next year with all course participants invited to attend to further build their knowledge and share experiences.

5. Conclusion

The participants of the WMTM training reported it increased their knowledge of and confidence in using human rights. It has to be recognised that the training was only one day with a two day train the trainer course and therefore the impact on practice will be limited.

The barriers experienced in the workplace and the difficulty experienced by some in maintaining knowledge of a complex subject made change all the more difficult. Barriers relating to ways of working require a change in culture that goes beyond education to ensure human rights are fully embedded and that the change is sustained. The training raises knowledge and awareness and gives people the language to use when applying human rights to practice situations and engaging others in the discussion; however the extent to which they act on this is variable.
Sustaining the learning and embedding human rights is an ongoing process. Participants mentioned the need for training to be available to the wider workforce and integrated into health professional student training. Refresher courses and other quick reference aids need to be available to maintain the knowledge.

“This needs to be an ongoing cycle of training not a once off event I feel. Needs to be embedded more across the healthcare environment”. Nurse

If human rights practice is to be embedded then a change in thinking and ways of working need to happen. It has been shown that the training programme has contributed to raised awareness, knowledge and confidence but without ongoing support this may not be sustained in the long-term. Barriers need to be overcome.

The themes raised in the data analysis would benefit from being explored further to understand more about the barriers to implementing human rights at end of life and how best to support people to maintain high levels of knowledge and confidence over time.

The initial WMTM training programme was funded for 3 years by the Burdett Trust which has now ended. Sue Ryder are committed to the delivery of human rights training to improve knowledge and confidence so the training will continue, however a fee has now been introduced to external applicants to contribute to cost recovery.

A further driver to continuing the training programme and implementing human rights in the workplace is the focus given to it by the Care Quality Commission (CQC) and the Care Inspectorate Scotland. The CQC Inspectorate Team has undertaken training on equality and human rights delivered by the BIHR and human rights is now part of regulation standards 14, by incorporating the human rights principles of fairness, respect, equality, dignity and autonomy to develop a list of human rights topics for each of the key lines of enquiry. The key lines of enquiry are used as the framework for CQC inspections to ensure that regulation standards are met.

To build on the success of the WMTM training, the following recommendations are made. There is a need to:

- Widen the reach of the programme through an online platform to deliver more training to empower more staff across diverse health and social care providers throughout the UK.
- Evaluate the impact of the training on practice and the impact on service users’ experience of rights-respecting care.
- Develop additional learning resources including short-form materials such as posters and bespoke resources for specific conditions and cases.

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14 CQC, Our human rights approach for how we regulate health and social care services: February 2019, 2019
“The training was thought provoking, stimulating and relevant. It was good to meet with other professionals and to take part in interactive discussions. I enjoyed the day and found it very useful”. **Social Worker**

“This session was really well organised, paced and delivered. It has really made me reflect upon my practice and has given me a tool kit for challenging others and ensuring that human rights issues are identified and addressed”. **Nurse**
Welcome to the Sue Ryder "What Matters to Me" training programme: a human rights approach to end of life care. You are due to attend one of our training events so we are asking you to complete this pre-course questionnaire. This forms part of our evaluation of the impact of the training and we will be contacting you again after the training to ask you to complete a post-course questionnaire. It is on submission of the post-course questionnaire that you will be able to download your Certificate of Attendance.

We will contact you one final time in approximately six months after your course, to complete a final questionnaire. At any point you can opt out by not completing a questionnaire.

This information is for the evaluation only and will not be seen by the course leader prior to the training. You are asked to include your name so that we may match the pre and post questionnaires but only anonymised data will be made available to the evaluation team or course leader.

No individuals will be identified in any report that is written.

The questionnaire should take no longer than 15 minutes to complete.

Thank you for your time and we look forward to welcoming you on the course.

1. Date of training course:
_________________________________

2. Name:
___________________________________________________

3. What is your current role?
Doctor
Nurse
AHP
Social Worker
Support worker/Health Care Assistant/Assistant Practitioner
Other (please specify): _________________________________

4. In your own words, what do you understand by a human rights approach to end of life care?
Appendix 1 – What Matters to Me – Pre course questionnaire

Perception of knowledge of human rights and their applicability
5. Please select the answer which best describes your response by ticking the box:
1 = not at all knowledgeable, 10 = very knowledgeable

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Perception of confidence of applying human rights to the delivery of care
6. Please select the answer that best describes your response by ticking the box:
1 = not at all confident, 10 = very confident

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### Perception of confidence in identifying a human rights issue in practice

7. Please select the answer that best describes your response by ticking the box:

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<th>Not at all true</th>
<th>Hardly true</th>
<th>Moderately true</th>
<th>Exactly true</th>
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<td>I feel confident to identify a human rights issue in practice</td>
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### Perception of putting human rights into practice

8. What do you think are the main barriers to implementing human rights in your work?

9. Please give an example of where you have used human rights in practice, or where you think there was a human rights issue.

10. What do you hope to get from the training event that you are going to attend on human rights?

11. Any further thoughts or comments you would like to share with us?

Thank you for taking the time to complete this questionnaire.
Welcome back to the Sue Ryder "What Matters to Me" training programme: a human rights approach to end of life care. Thank you for attending one of our recent training events, we hope that you enjoyed it. Please can you complete this post-course questionnaire? This forms part of our evaluation of the impact of the training, so it is very helpful to us that you complete the questionnaire. It is on submission of this questionnaire that you will be able to download your Certificate of Attendance.

We will contact you one final time in approximately six months after your course, to complete a final questionnaire. At any point you can opt out by not completing a questionnaire.

You are asked to include your name so that we may match the pre and post questionnaires but only anonymised data will be made available to the evaluation team or course leader.

No individuals will be identified in any report that is written. The questionnaire should take no longer than 20 minutes to complete.

Thank you for your time and please do share any stories of how you have used human rights in practice with us. Please send any stories to humanrights@suerydercare.org

Name: ____________________________________________________

What is your current role?
- Doctor
- Nurse
- AHP
- Social Worker
- Support worker/Health Care Assistant/Assistant Practitioner
- Other (please specify): ________________________________

In your own words, what do you understand by a human rights approach to end of life care?

Date of training course: ________________________________
### Perception of knowledge of human rights and their applicability

Please select the answer which best describes your response by ticking the box: 1 = not at all knowledgeable, 10 = very knowledgeable

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### Perception of confidence of applying human rights to the delivery of care

Please select the answer that best describes your response by ticking the box: 1 = not at all confident, 10 = very confident

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<thead>
<tr>
<th>Question</th>
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Appendix 2 – What Matters to Me – questionnaire 2 weeks post training

Perception of confidence in identifying a human rights issue in practice

Please select the answer that best describes your response by ticking the box:

<table>
<thead>
<tr>
<th>Not at all true</th>
<th>Hardly true</th>
<th>Moderately true</th>
<th>Exactly true</th>
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<tbody>
<tr>
<td>I feel confident to identify a human rights issue in practice</td>
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</table>

Perception of putting human rights into practice

What do you think are the main barriers to implementing human rights in your work?

Please share your top 3 things you did differently or any other changes you have made in practice as a result of the training?

Impact of human rights training

Please select the answer that best describes your response by ticking the box:

Since attending human rights training, do you think that what you have learnt has helped you:

<table>
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<tr>
<th>Yes</th>
<th>No</th>
<th>Maybe</th>
<th>N/A</th>
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<tr>
<td>Balance risk in decision-making</td>
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<td>Deliver better person-centred care</td>
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Since attending 'What Matters to Me', have you used the decision-making flowchart in the Practitioners Guide? YES/NO. If you have answered YES, please can you tell us how you have used the flowchart in practice?

Please comment on any further training needs you have identified in relation to human rights or resources you would find helpful, since the training?
On reflection, any further thoughts or comments you would like to share with us?

Further Research
We would like to speak to you again in a few months to find out about ways in which this training has impacted on your role. Your continued input into the evaluation is greatly appreciated and will impact on the future roll-out of this training.
You attended a Sue Ryder training workshop "What Matters to Me": a human rights approach to end of life care, approximately six months ago.

If you are happy to be contacted to take part in a short interview please tick the box below and provide your contact details. Please note that by providing contact details you are not committing to be involved in further research and future participation remains optional.

I am happy to be contacted to explore these issues in greater depth and discuss the impact of this training on my role and understand that I can opt out of participation at any time.
Appendix 3 – What Matters to Me – questionnaire 6 months post training

We are asking you to complete this six months post-course questionnaire. This forms part of our evaluation of the impact of the training. It is very important to us that you complete this final questionnaire.

This information is for the evaluation only and will not be seen by the course leader. You are asked to include your name so that we may match your previous pre and post questionnaires but only anonymised data will be made available to the evaluation team or course leader.

No individuals will be identified in any report that is written.

Date of training course: ________________________________

What type of training workshop did you attend?

☐ 4-hour non-registered workforce workshop
☐ 1-day registered workforce workshop
☐ 2-day train the trainer workshop

Name:
_____________________________________________________

What is your current role?

☐ Doctor
☐ Nurse
☐ AHP
☐ Social Worker
☐ Support worker/Health Care Assistant/Assistant Practitioner
☐ Other (please specify):

In your own words, what do you understand by a human rights approach to end of life care?
**Appendix 3 – What Matters to Me – questionnaire 6 months post training**

### Perception of knowledge of human rights and their applicability

Please select the answer which describes your response by ticking the box:
1 = not at all knowledgeable, 10 = very knowledgeable

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<tr>
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Appendix 3 – What Matters to Me – questionnaire 6 months post training

**Perception of putting human rights into practice**

What are the main barriers you have found in implementing human rights in your work?

Please share up to three things you have done differently in practice since the training:
1. 
2. 
3. 

**Impact of human rights training on you**

Since attending human rights training, do you think that what you have learned has helped you:
Please select the answer which best describes your response by ticking the box:

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**Further Research**

We would like to speak to you to find out about the ways in which this training has impacted on your role.

If you are happy to be contacted to take part in a short interview please tick the box below and provide us with your contact details.

Your continued input into the evaluation is greatly appreciated and will impact on the future roll out of this training.

Please note: by providing contact details you are not committing to be involved in further research and future participation remains optional.

☐ I AM HAPPY to be re contacted to explore these issues in greater depth and discuss the impact of this training on my role and understand that I can opt out of participation at any time.

Please provide your name and contact details:

Name: 
Telephone number: 
Email address: