



End of Life Doula UK Evaluation

Leeds and Surrounding Areas
NHS Commission

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1. Executive Summary

End of life doulas provide support to those with terminal or life-limiting illness and those around them, as well as communities around issues of death, dying and bereavement. Since 2022, End of Life Doula UK (EoLDUK) has been commissioned by NHS West Yorkshire to provide doula services within Leeds and the surround areas based on a set funding amount. The commission reflects a novel approach to offering end of life care under NHS funding, by using doula services to offer flexible person-centred support. The commission and evaluation have adopted a pilot approach. To date (July 2023), half of the commission is complete with 173 clients being referred. This report summaries and evaluates the commission to date, noting examples of clients, what type of support doulas have provided, and reporting on the outcome measures.

2. Introduction

2.1 Issues of End of Life Care

The UK is noted as being world-leading when in end-of-life care;¹ however, it is recognised within the country that access is not equitable and that more could be done to improve the quality and timing of end of life.² Due to this, interventions in how care is provided are needed: these can range from quality improvement projects, research, and policy changes. The Ambitions for Palliative and End of Life Care: a national framework for local action encourages innovating locally to generate improvements, including rethinking how and when people are supported at the end of life and by whom. This report is about one such innovation – commissioning of end of life doula services from End of Life Doula UK within Leeds and surrounding area.

2.2 End of Life Doulas and End of Life Doula UK

End of life doulas provide support to people with terminal or life-limiting illness and those around them, as well as communities around issues of death, dying and bereavement. Nationally and internationally, there is considerable variation in what kind of services and support doulas provide and the role is not professionalised.^{3,4} Demand for doula support at the end of life has been seen to increase; for example, prior to this commissioned service, End of Life Doula UK noted referrals increasing by 53% from 2019 to 2020 and continuing to rise. This section describes what End of Life Doula UK is and what the doulas within this organisation do.

End of Life Doula UK (EoLDUK) was established in 2018. It is the membership organisation and community of practice supporting end of life doulas in the UK, and as such, a leading organisation for end of life doulas across the country. EoLDUK act as a central point of contact for members of the public (and health and social care professionals) seeking end of life doula support. They also provide community workshops and education around death and dying and advance care and death planning.

EoLDUK champion a 'person-centred' approach to end of life care – where attention is paid to both the individual and their community, avoiding potentially negative aspects of over-medicalisation. End of Life Doulas are independent freelance workers who offer practical, emotional and (if desired) spiritual support to individuals at the end of life and those important to them (e.g. family and friends). They can help people navigate the end of life. Doulas aim to be a consistent and flexible presence, able to fill gaps in existing support (e.g. in addition to what may be provided by families, NHS services and social care). Typically, within EoLDUK, the services provided range from free provision of support to some doulas charging a fee for their service (as they are self-employed).



End of Life Doula UK champions a person-centred approach to end of life care.



2.3 Background to the Pilot

EoLDUK was commissioned by NHS West Yorkshire Integrated Care Board to provide doula services within Leeds and the surrounding area. The contract was signed in Spring 2022 for £50,000 that would fund 1500 hours of doula support and some administrative time. The doulas remain self-employed and are paid via EoLDUK for the hours of support they provide. At the start of the commission, there were four doulas operating in the Leeds area. The referrals began to be received in May 2022.

As part of the commissioning process, EoLDUK discussed with the commissioners several outcome measures. These were designed with the following principles in mind: what standard end of life doula support looks like; how end of life care is quality measured; creating outcomes measures that align with doula practices. It was agreed early on that that whilst EoLDUK would report on these outcome measures, that they were not to be used as strict key performance indicators to honour the flexibility of the pilot. The outcome measures and performance against them is discussed in more detail in Section 3.2.

2.4 Evaluation Information

To help understand how the end of life doula service worked in this area and what kinds of impact it may have had, EoLDUK partnered with researchers at The Open University to evaluate the service. This has been a responsive evaluation that has adapted as the service has adapted, but has focused on several key areas. Firstly, the research team has provided guidance around

understanding outcome measures and how to measure quality end of life care, including advice about the difficulties of outcome measures in end of life care. Secondly, the team designed a survey to be used by EoLDUK to gain feedback from the carers/family/friends after a death; the team have also supported the data collection and analysis for this. Thirdly, the team held two events (focus group and Collaboratory) with doulas in Leeds to gather data about their role, their experiences of providing doula services, and examples of practice. Full details about all data collection and analysis can be obtained by contacting the evaluation lead (EB); data collection was reviewed by the OU HREC. Fourthly, the research team have provided expert support in data analysis of routine data. Additionally, the team have supported EoLDUK to reflect on the service, areas of business and strategy growth, and collaborative working. Lastly, the research team have led on drafting this report and related outputs from the project.

3. Findings

3.1 Overview of Doula Support and Impact

To establish the service in the area, EoLNUK presented the service at GP offices, local community health teams, local hospitals, and liaised with the Health Case Management Team. EoLNUK began to receive referrals from services from late June 2022 onwards. By 1 July 2023, 173 clients were supported by the service.¹ The number of doulas supporting the service increased from four to 11 during this time with many working part-time as doulas; more are in training. Doulas typically supported clients that were geographically close to them rather than each doula covering the whole area; not all areas are equally accessing the service but initial data suggests that there are higher numbers of clients from areas of known social and economic deprivation. In Section 3.4 below, we outline several cases to exemplify the contexts in which doula support has been provided and to illustrate types of clients supported.

All referrals were directed to EoLNUK; these were noted and sent out to the local doulas. The service received referrals from several sources, with the most frequent referrer being the [Health Case Management Team](#). This team provides support for people who are eligible for NHS Fast Track and Continuing

¹ This data was provided to EB during a meeting between EoLNUK and EB.

Healthcare Funding and have a Leeds GP. This resulted in many referrals that were for people who were recognised as being in the last weeks of life; some referred clients were unable to be supported by doulas because they died before the first support visit/call. EoLDUK also received referrals from [Neighbourhood Teams](#), which focus on reducing hospital stays and reducing use of long term social care. EoLDUK acknowledge the promotion of the service and fostering relationships with referrers influences the referral volume, which geographic areas are covered, and types of clients referred.

Doula support by its very nature is multi-faceted and flexible around the person; it is also influenced by the skill set provided by each individual doula and their capacity to provide different types of support. Through conversations with EoLDUK, the focus group and the Collaboratory, we noted that doulas provided a mix of practical, emotional, and spiritual/existential support, and assistance to the wider social and professional network around the client. The nature of support can change throughout the time of supporting the client and can extend into bereavement. Examples of support include, but are not limited to: advance care planning conversations and documentation; support making wills; moving furniture and taking some items to charity shops; support with claiming disability allowance and carers allowance; telephone calls to listening to concerns; dog walking and small errands; attending clinical appointments with client; and being present in the home (e.g. respite for carers). Additionally, the doulas noted that one of the aspects of their role is to help people navigate systems and therefore the doulas liaise with other organisations including health and social care, third sector, local authority, and post-death services like funeral homes.

3.2 Outcome Measures

The outcome measures were owned by EoL DUK. The data to measure them was generated through 'routine data' collected by the service from each doula about each client who used the service. The OU team provided guidance on how to measure the data.

Table 1 below demonstrates the outcome measures based on data supplied about clients seen up until 1 July 2023. It only includes clients for which there is full data for measures 1-3; measure four is covered in the section below.

TABLE 1: Outcome Measures, Targets and Current Progress

Outcome	Measure	Target	Current
1. Individuals who have support from an End of Life Doula will receive coordinated, planned care at the end of life	Patients supported by EoL Doula avoid unplanned admissions to hospital in the last three months of life	<20% will have hospital admission	6% were admitted to hospital
2. Individuals who have support from an End of Life Doula will have good quality, up to date Advanced Care Plan (ACP) in place	Patients supported by EoL Doula who die with an ACP in place or documented as not taking part in the conversation with reasonable attempts made to put ACP in place.	100%	84% have had ACP conversations
3. Individuals who have support from an End of Life Doula will achieve their preferred place of death (PPOD)	Patients supported by EoL Doula who achieve PPOD	90%	75% died in preferred place
4. Family members/informal carers will feel heard/involved/empowered/supported/less anxious if they have support from an End of Life Doula	Carers Survey to be developed by EoL Doula UK	100%	Not yet available

The outcome measures set by EoL DUK at the start of the project were regularly discussed between Emma (EoL DUK) and Erica (OU). This enabled an ongoing reflective dialogue about how the service was evolving throughout the commission; in this, three issues have been noted which are described below.

Firstly, the use of routine data was helpful for minimising data input/collection burden for the doulas. However, it was still noted that there was missing data.

Reasons for this included: doulas not prioritising this task, doulas unsure of what

to put for various clients (unclear information from client, unclear what requirement was for data point, unable to do advance care planning with client), and the short duration of support for some clients.

Secondly, several months into the project it became evident that the type of referrals that were being sent to EoLDUK did not reflect their 'typical' doula provision. The two main differences were: that they were receiving referrals for people who were in the last week of life and/or that some clients (or their family/friends) only wanted one-off telephone support. The outcome measures were not designed to capture these types of client dynamics.

Thirdly, the commissioners' interest in the project changed over time. This change in interest reflected changes in personnel, shifting local priorities, a recognition of the flexible and fluid nature of doula provision, and a desire to 'learn with' EoLDUK. Human Learning Systems note the value of learning together in commissioning models to address 'wicked or messy' challenge.⁵ Some of the issues that commissioners became interested in was information about which geographical areas were being supported, what organisations the doulas were linking with, and information about kinds of support. These interests reflect more of a process-focus rather than outcome measures; a shared journey alongside those taking a strategic look at areas of need.

3.3 Bereavement Survey

The survey was designed in 2022 and available to EoLDUK from 1 July 2022 onwards. The survey is online and paper copies are available if required. The survey contains 18 questions; they are a mix of open and closed questions to

enable both a measure of support as well as free text commentary. A version of the survey was pilot tested by a previous client of EoLDUK. A fully copy of the survey questions can be [found on ORDO](#).

Based on EoLDUK's expectations of how the services in Leeds would work, the survey was designed to be supplied as a link (or paper copy if needed) to the bereaved carer/family/friends. The doula working with them would supply the link after the death (up to three months after the death) and reassure them that all responses would be anonymous. Additionally, the survey introduction makes it clear that responses will not be shared with the individual doula. To encourage full consent, only answers from respondents who click 'submit' at the end of the survey are recorded.

To date (01/07/23), no online or postal responses have been received. It is evident that some people have viewed the survey link. Given the lack of data recorded, we tested the survey system which was found to be working.

Discussions with EoLDUK indicate that there are several potential reasons for the lack of response. This includes gatekeeping by doulas who may feel it was inappropriate to send the link to some clients' social networks, either based on lack of sustained engagement with the doula or other factors, as well as survey recipients not wishing to complete the survey for various reasons. Lastly, it should be noted that many of the clients supported by EoLDUK during the pilot did not have close family/friends who would be eligible to fill in the survey; the service is supporting people who are deemed to be socially isolated.

3.4 Client Case Examples

To help illustrate what doulas in Leeds and the surrounding areas are doing, we have collated four case examples. These are based on composite cases (i.e. reflect several clients seen by the doula service). Composite cases are useful to highlighting patterns in the types of support doula provide and the issues clients encounter, as well as showcasing how doula support can make a difference for people. The information to generate these cases has come from discussions with EoLDUK about the routine data, the focus group, and the Collaboratory; in the latter event we specifically created a [composite template](#). The use of composites here also honours the doulas' concerns about protecting client and doula confidentiality.

Client Example 1

Person and their context: Older man (late 70s or early 80s) with several multi-mobilities and terminal cancer diagnosis. Recent history of frequent hospital readmissions, with general sense of inability to consistently live independently. Longer term history of alcohol consumption that negatively impacts health outcomes. Healthcare providers are not aware of any close family or friends that provide informal care and support.

Referral pathway: Healthcare providers refer directly to EoLDUK whilst he is still in the hospital.

How doula supported the client and differences noticed: Doula provides daily visits whilst in hospital. Ward staff notice change in his mood and shift in willingness to be discharged home. Once home, the doula continues weekly

visits and accompanies him to consultant out-patient appointments. This regular support enables them to develop a trusting relationship and the man reports increased self-confidence and better daily mood. By attending clinical visits, the doula can support his understanding of his conditions, actions he can take to help manage them, and do advance care planning. This helps him to have longer periods outside of hospital (and avoid admissions at times), reduce alcohol consumption, and manage better within the home. He sees the doula as a 'safety net' and feels increased self-worth as someone has taken an interest in his daily life and wellbeing.



Client Example 2

Person and their context: Older person with gradual deterioration of their condition to an extent where they now require more regular care with tasks of daily living. It is advised that they move into a care home from their own home, with the knowledge that they are likely to die in the care home within the near future. Few, if any, family/friends/neighbours locally that can support this transition between locations, especially with the practicalities of moving material possessions.

Referral pathway: Health Case Management Team (noting increased need now locally due to changes in other services availability and provision, both of social care hours and support with moving)

How doula supported the client and differences noticed: The doulas are able provide support both with the practical tasks of moving, as well as supporting the emotional journey people experience as they transfer into a care home with the awareness of their mortality. In terms of material possessions, doulas can help identify which items to move, help arrange transport (and/or move items) and help to dispose of items that are left. This support is highly valued by clients who feel that it helps them 'tie up loose ends' and take care of a task that may be 'beyond them' at this stage of their life. For some, there is a sense they cannot have a good death until they feel they can let go, which providing a resolution about material objects can help facilitate. On an emotional side, doulas also help clients make sense of what the transition means for them personally, including those who may be reluctant to move to a care home, and

have discussions about advance care planning. During this time doulas are also linking with other services to help with this transition.

Client Example 3

Person and their context: Older woman with no family geographically close. Multiple diagnoses, including respiratory failure and terminal cancer. Lives alone and identified by healthcare professionals as experiencing progressive decline and likely to be near the end of life.

Referral Pathway: Health Case Management Team

How doula supported the client and differences noted: Client unsure if they needed doula support; doula able to clarify any misconceptions about their role, which helped put client at ease. Doula listened to client's concerns about their situation and started conversations about what is important to them. Referral received close to death so only support was via 1-off telephone contact. Although offered, no next of kin/family asked for additional doula support.



Client Example 4

Person and their context: Older person with gradually declining health over last few years placing long-term strain on family. They live in a multi-generational household.

Referral Pathway: Referral by hospital palliative care team. Referrers recognised need for support both for client and the family. The person was not within the last few weeks of life.

How doula supported the client and differences noted: Since the referral was made at time when the client was not imminently dying, the doula was able to support the person and family in lead up to death in a range of ways that was found to help reduce the 'burden of care' on the family. Doula linked the family with a range of professionals to ensure they were supported as much as possible by relevant services. Doula also helped in the house with practical tasks at home, such as shopping and dog walking. This complemented the emotional support provided by listening to people's concerns. When death was closer, the doula spent time with the dying person enabling them to feel more relaxed and the family to be less worried about the person dying alone. This was felt to help the dying person feel 'released'. The doula also provided practical support after the death including helping contacting funeral home.

3.5 Evolving Doula Practice

During the KTV funded evaluation period, the research team from The Open University held two events with doulas working in the Leeds area. The first was an in-person focus group held in November 2022 with four doulas; latterly, a Collaboratory² using workshop methods event was held online in June 2023 with three doulas and head of EoLDUK. Both events were recorded, anonymised and transcripts analysed for salient themes presented below.

Within the focus group, we noted the following themes: professional boundaries and responsibilities; identity and role as doula; making sense of what doulas do; emotional intelligence and intuition; community of practice; experiencing death and dying; and Leeds evaluation. These themes were used to inform the Collaboratory which focused on further exploring the doula role, case examples (i.e. informing those outlined in Section 3.4), and their experiencing of supporting people with death and dying. The themes are presented jointly below.

² The Collaboratory involved a series of activities to explore at greater depth some of the main themes emerging from the focus group held in November 2022. The first two activities made use of an art-based approach⁶ as a form of qualitative enquiry: a) doulas were asked to send the research team a photograph which represented something about their roles; b) doulas were asked to draw on the whiteboard an image, a series of words, whatever came to their mind when reflecting on the emotional impact of working with people who were dying. This approach was used to generate, interpret and to share new understanding about the work of the EoLDUK. The third activity involved the doulas completing several composite templates, as listed in the report, of potential patients whom they may support.

Professional boundaries and responsibilities

The doulas feel a responsibility for the work that they do that is both directly related to their clients but also to the wider community. They felt that the service they are providing – along with this evaluation – serves to represent what end of life doulas are, even as the pilot is unfolding. As part of this, the doulas were mindful of how what they said in the focus group may be interpreted by others and were keen to ensure confidentiality. This informed our use of case composites rather than focus on specific individual client examples.

Doulas noted that a key aspect of their role is managing relationships with other professionals on behalf of clients and EoLDUK. The doulas noted that other professionals may not fully understand what the doula role is and can misrecognise them at times; at times, this could feel disrespectful. The doulas noted that how other services thought of the doula role depended on the relationship developed between EoLDUK/doulas and the other service, including the notion that at time doulas were being called in to ‘plug gaps’.

Moreover, they are balancing their doula role with other professional roles they may hold through employment (often in the same locality), especially as the doula role is ‘non-medical’; in this, the doulas have a high degree of independence in terms of how they balance roles. This multifaceted nature of professional boundaries and responsibilities meant that doulas are still in a process of exploring and articulating the complexities of what ‘end of life doula’ is and means for them.

Identity and Role as Doula

This theme has links with the previous theme about boundaries and responsibilities; the difference is that this theme focused more on what it means to be a doula. As one participant summarised it, 'to me, it's a way of being, not just a role' (FG participant). The identity of a doula then is tied up in ways of being and not just about holding the 'role of doula'. This was further elaborated on in terms of how they 'be': 'it's being alongside people' (FG participant). It was also noted that this required a certain way of being: 'how do I witness someone and not try and fix them, not try and change them, not try and direct them, and that's a monumentally big task' (FG participant). In the Collaboratory, being alongside aspect of the role was further elaborated into an interconnected oppositional balance metaphor of supporting living well and dying well.

Furthermore, the doulas expressed how their role is flexible and different every time, adapting to what clients need, and that this was very clear in the Leeds project. Whilst the doulas welcomed this flexibility, some also noted that it can be daunting as it means there can be a lack of clarity about what is expected of them, and that this goes beyond their initial training as doulas; it could also be tricky for them in terms of managing client and system expectations of doula time. Additionally, we noted that there was variability in terms of how long doulas had been practicing and that for some they were still developing what the role meant to them. Importantly, whilst the doulas spend considerable effort telling clients what a doula is and does, they noted that not everyone retained this information and may assume they are from another service such as hospice.

Making Sense of What Doulas Do

Building on from the sense of their role and identity, the doulas talked about 'being alongside' clients, as well as the range of practical, emotional, and relational support that they provided. Practical support included support with household tasks, paperwork, and liaising between services; the practical side of support was considered to be more prominent in the Leeds work than other doula provision they had provided. Emotional support included listening and feeling trusted with things that someone may not be able to tell others. Relational support included supporting families and those around the dying person. A key difference the doulas noted between their role and what other professionals may provide is the ongoing support for the client and family, including into bereavement. Doulas also accepted that sometimes they could 'not make a difference', either due to short period of time between referral and death or because someone did not want the type of support the doula was able to support (and conversely, doula could not provide support needed, especially if culturally specific in terms of language).

Emotional intelligence and intuition

One aspect of their role and support that the doulas frequently mentioned is the emotional aspect. To do this well, doulas commented on the importance of presence and listening, and that this began from the first contact they had with a client. Doulas would use their own intuition based on interaction to help guide their next actions, such as suggesting a visit or provide some mediation. Doulas noted the power of talk and enabling others to talk; that through talk people

could process their situation and start to problem solve. Others called this intuition pattern recognition and noted how it develops with experience in the role.

Community of Practice

Day-to-day the doulas work fairly independently. The research activities provided them a collective reflexive space that they valued for sharing experiences. They noted supportive practices that they provide for each other, through regular text messaging and support via EoLDUK. The ability to support each other was recognised as being constrained at times by the various roles and responsibilities doulas may have that can make time for each other difficult to find. The doulas noted that they themselves did not know the diversity of the skill set of the doula team, and that knowing this could improve how they ask for and provide support for each other.

Experiencing Death and Dying

This was an element that featured in the focus group discussions that was further explored in the Collaboratory via a creative activity. Due to the nature of the work, especially in Leeds with 'late referrals', the doulas are developing relationships with people who soon die. This can be viewed as challenging by some, both in terms of the need to build rapport but also the quick detachment that happens due to death. Even when death was expected it could be experienced as surprising or more sudden than anticipated. At times, experiencing a client's death can leave doulas feeling like they do not personally have closure after a client's death or before needing to support

others. In much of the discussions, the doulas do not overtly recognise the emotional impact of their work on themselves; at times, the discussion focused more on supporting others (such as family) at this time. Processing one's own emotions was very individual, reflecting their own differing spiritual, personal, and social practices around death.

Leeds Project: Culture and Practice

The doulas noted that clients and their families (if present) often thank them after each interaction (and from the family after the client's death). The doulas were less sure how much such gratitude is formalised in evaluation methods and also speculated that at times it can be cultural practice, especially in circumstances where doula felt they had not provided much support. The doulas expressed a difficulty in knowing if they had 'done a good job'. This illustrates a tension in doula provision around difficulty in knowing and assessing both impact and gratitude.

Part of the conversations also focused on reflecting about how practices were working in Leeds. The doulas' main concerns and recommendations were focused on the referral process. This included the timings of referrals, who was matched with whom, and uncertainty about time commitments required for each client due to the flexible nature of doula provision. Doulas expressed a desire to have a longer time to work with clients to develop rapport and provide a wider range of support.

4. Lessons Learned

There are several 'lessons learned' from this evaluation that are relevant both to EoLDUK and those who are considering commissioning such services in the future. Foremost, the flexibility of the commissioning set-up for this pilot was useful in that it enabled the service to grow at a pace that did not overwhelm the doulas. Moreover, the pragmatism about outcome measures was useful as this enabled a more reflexive approach to service provision.

As evidenced in the case examples, the doulas provide a range of support. We have noted that this can improve someone's wellbeing – both for the client who is dying but also for those around the – as well as reduce hospital admission. More data would need to be collected to understand the full scale and capacity for doula support (especially compared to other services). Nevertheless, there is an indication that the doula service can support people to live and die well in a manner that is aligned with the local integrated care board's objectives and values.

From a systems perspective, we have observed that the flexibility of the doula service has meant that the support they provide not only flexes around the client, but also around what other support is available or not at the time. For example, when an existing service that helped people move into care homes stopped, doulas began picking up that kind of support as well. In this way, the doula service could 'fill the gaps' at times. However, it should be noted that this is only possible when the doulas have the capacity and available resources to do this, and not all individual doulas would be able to provide such support.

Relatedly, the flexibility of the doula support is partly attributed to the wide range of skills that doulas bring with them as individuals. Doulas are provided training by Living Well Dying Well around death and dying; however, many doulas also bring with them practical life skills that can be supportive. This can include administrative duties, practical home helps and animal care, and their ability to network locally with different organisations and services. This richness in skills is an asset for doula-based care but it also means that there is inevitably variation in what is possible to provide which is not driven by client need.

There are three main lessons around referring processes. Firstly, establishing local links with potential referral makers is crucial. This takes time as it requires sharing information about the service and what doulas do, and building a relationship between EoLDUK and potential referrers. Due to the nature of the needs of people towards the end of life, who are often considered 'vulnerable', referrers want to ensure that the doula service is trustworthy, reliable, and supportive of people. They also need to have a good enough understanding of what the service is and what doulas do in order to inform potential clients of the service. We noted that as these relationships were developed, it increased the rate of referrals for EoLDUK. A recommendation for similar commissions in the future is that commissioners provide more time and practical support to enable the building of these relationships; joint meetings and introducing the doula service can improve pick-up as it is not perceived as 'cold calling'.

Secondly, the type of referral impacts the kinds of support doulas tend to provide. We noted that the service received a higher-than-originally-expected

number of referrals for people in their last week of life. This gave the doulas relatively little time to do tasks they would typically try to do with clients, such as advance care planning. Referrals made earlier in the client's trajectory would enable doulas to establish more rapport, do more supportive tasks for the client and those around them, and establish relationships that can be supportive into bereavement. Although not explored in great extent with the doulas at this stage, we are also mindful that there is the risk of burnout when having to quickly establish relationships with people within days before they die and doulas may experience a disjunction between their expectations of their role and what occurs within such referrals.

Thirdly, if there is more time between referral and time of death, this enables a longer opportunity to match a client with a doula. The matching process for this commission has been around doula availability and locality. Other variables for matching could also be taken into a consideration, including matching client needs to doula skills sets and preferences.

The doula service provided many clients and those referred to the system with telephone support; for some people, this was the only form of support their received. This made it difficult for doulas, at times, to engage with people in a way that met the objectives of the outcome measures, including doulas feeling it was inappropriate to ask family/friends to complete the evaluation survey. In the future, there is scope to examine in more detail what this support is like and what training and support needs doulas may have around providing telephone support.

Lastly, there are lessons learned about the costing of the pilot. At this point, approximately half of the money has been spent (£25,000); equating to approximately £145 spent per client covering both doula time and administrative time. The flat fee paid to EoLDUK for the commission enabled the organisation to pay doulas as needed/used, which is useful as doulas are freelance and independent, rather than salaried employees. The amount of money set aside for administrative duties would have benefited from being a larger proportion of the overall commission to adequately reflect the time it has taken to develop relationships with referrers, manage incoming referrals, support the doulas, and manage the data. From a business perspective it is also vital that not all key roles are run through one person as can become a single point of failure if that person is unwell, on leave, on so forth. In the future, should the commission continue in Leeds or other areas, a dedicated role for managing referrals would be useful as this would make the workload for EoLDUK more manageable and provide more administrative support for the referrers, clients, and doulas.

Top tips:

- **Keep outcome measures flexible or be pragmatic about objectives**
- **Invest in developing relationships with potential referrers**
- **Consider what mechanisms are used for matching clients with doulas**
- **Commit more resources to administrative support**

5. Conclusion

End of life doulas can provide a range of support to people who are dying (and those close to them where applicable). Doula support is flexible both in terms of flexing around what a client needs but also being wide ranging depending on the skills of the doula, timing of the referral, and relationship developed between doula and client. In this project, we noted that the doulas can also provide a useful linking function between services and 'fill gaps' in wider end of life and death systems. Whilst doula support is difficult to concretely capture with outcome measures, preliminary analysis presented here suggest that it can support people to die in accordance with their preferences and reduce hospital admissions.

Of note, the type of referrals received by EoLDUK during this pilot vary considerably to what doulas typically receive. In the Leeds project, many referrals are made within the last week(s) of life by an external referrer; typically, doulas receive self-referred clients who have months to live. This has impacted the type of support doulas have provided and tracking against the set outcome measures. It has also led to considerations about what the dual role is about and how doulas understand the impact of their support. If similar commissions are to be done elsewhere, more resources need to be dedicated to establishing relationships with potential referrers and managing the referral process.

6. References

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