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Advance care planning in perinatal settings. National survey of implementation using Normalisation Process Theory.

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Abstract

Background Perinatal Advance Care Planning (PnACP) is a process of formal decision-making to help families plan for their baby's care when recognised that they may have a life-limiting condition. While PnACP is recommended in policy, there is a lack of evidence to support implementation and development in the perinatal setting.

Objective To conduct an online survey of UK and Ireland perinatal providers to examine how PnACP is operationalised in current practice.

Methods A secure online questionnaire was developed to collect data on (i) 'what' is being implemented, (ii) the 'processes' being used, (iii) perceived impact and (iv) unmet support needs. Data was analysed using basic descriptive statistics, thematic analysis and through a conceptual lens of Normalisation Process Theory.

Results Questionnaires were completed by 108 health professionals working in 108 maternity and neonatal services; representing 90 organisations across the UK and Ireland. This revealed many resources and examples of good practice to support PnACP. However, there was wide variation in how PnACP was conceptualised and implemented. Existing frameworks, pathways and planning tools are not routinely embedded into care, and respondents identified many barriers that negatively impact the quality of care. They called for better integration of palliative care principles into acute settings and more investment in staff training to support families at existentially difficult times.

Conclusions Priorities for additional perinatal service development include greater sharing of best practice and effective strategies to target the unique challenges of PnACP, such as time-sensitive collaborative working and decision-making in the face of high uncertainty.

Background

The importance of integrating palliative care into maternity and neonatal services is increasingly acknowledged [1-4]. For example, Together for Short Lives have worked with multiple stakeholder groups to produce a perinatal care pathway for babies with life-limiting conditions [2]. This defines palliative care as 'an active and total approach to care' that 'embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life' [2]. It also recommends that palliative care provides 'integrated ongoing support from the diagnosis of a life-limiting condition in a fetus, and during pregnancy, delivery, postnatal care, and (if needed) bereavement care' [2].

In the UK, this is underscored by two sets of evidence. Firstly, the prevalence of life-limiting conditions in children is greatest in the under 1-year age group, as is the number of deaths; suggesting that 'this group should be seen as a priority for receiving palliative care' (p.46) [5]. Secondly, advances in pre-natal care and technology, means that increasing numbers of expectant parents are faced with the devastating news that their unborn baby may have a life-limiting illness [6].

Perinatal advance care planning (PnACP) is recommended as an essential component of care for these babies and families, including in the UK [1,6] where it is central to the Perinatal Pathway for Babies with Palliative Care Needs [2]. PnACP is a formal decision-making process over a series of conversations offering professionals an important opportunity to share clinical information, options and expectations with parents. It allows parents and healthcare professionals to jointly plan what care provision and interventions would be most appropriate in a range of potential future scenarios, including deterioration of the baby's condition, emergency events and end of life care. It is an opportunity for parents to consider what their priorities would be if their baby's life is likely to be short or if their baby is dying [2,3]. PnACP can also be used when there is diagnostic/prognostic uncertainty [2]. As such, PnACP is applicable to a range of conditions including congenital malformations, extreme prematurity and other complex problems [2].

Although advocated, an evidence review identified no high quality studies specific to PnACP [1,7]. The case for addressing this is compelling. Parents value honest communication about prognosis and cope better when involved in parent-centred decision-making [8-12]. Earlier recognition of end-of-life is associated with less suffering in babies and better parental outcomes, whereas lack of support increases parents' risks of long-term psychological and physical morbidity [13-15].¹³⁻¹⁵ Ineffective communication can also cause moral distress and staff burnout [16, 17]. Moreover, emerging evidence suggests that PnACP can be acceptable to parents and staff,¹⁸ but uncertainty exists about the right approach [19].

This study consequently aimed to identify (i) how PnACP is understood and enacted across maternal, neonatal and palliative care settings, and (ii) how individuals and organisations can influence the quality and experience of care for the benefit of babies, parents and professionals.

Methods

Design

A cross-sectional survey was undertaken, informed by Normalisation Process Theory (NPT) [20]. This proposes 4 constructs (with 16 sub-dimensions) to understand how complex interventions, like PnACP, become embedded and routinised in clinical practice. The first two are 'planning phases' of work [21], where individuals, as part of social groups, try to make sense of new practices (*Coherence*) and organise themselves around the ideas, objects and requirements of these (*Cognitive Participation*) [20]. The latter two are 'doing phases' [21], where people undertake the practices (*Collective Action*), evaluate them and take responsive action (*Reflexive Monitoring*) [20].

Survey tool

A secure online questionnaire was designed using REDCAP [22]; following best practice [23]. Items were informed by: NPT; a review of national policies, pathways and guidance [2,6] and the Template for Intervention Description and Replication (TIDier) Checklist [24]. The resultant questionnaire collected data on (i) participant and organisational characteristics, (ii) PnACP implementation, (iii) PnACP resources, (iii) perceived impact and (iv) unmet support needs. It used non-randomised adaptive questioning, was pretested by NHS and hospice staff (n=7), and administered in 2021 over 3 months.

Setting and sample

All UK maternity and newborn services represented in the perinatal palliative care pathway [2] were eligible to participate. The exact number of eligible services was not known. However, the sampling frame was based on UK Neonatal Collaborative [25] data which, at the item of study, had mapped 246 neonatal services. These included neonatal intensive care units (n=61), special care units (=39) local neonatal units (n=86), children's hospitals (surgical neonatal only) (n=6), children's hospices, including 3 baby hospices (n=54), fetal medicine services (n=30).

Invitations to participate were cascaded by relevant professional organisations, clinical networks and charities who forwarded the survey-link to their membership or via newsletters or social media. Service leads were invited to co-ordinate completion. Participants were able to save, review and change answers while the survey was open. All questionnaires were accepted, including partial completions.

Analysis

Analysis employed SPSS [26], using standard descriptive statistics to describe key features of the quantitative data. Qualitative data were analysed using directed qualitative content analysis [27]. Documents shared (e.g. PnACP pro-forma/templates) were analysed using summative content analysis [27].

Patient and Public Involvement

The proposal was informed by leading charities, and discussions with baby hospice staff and five mothers (3 bereaved) who confirmed the study's relevance.

Ethics

A favourable ethical review was given by the University of Birmingham (ERN_19-1192) (as was considered service evaluation by the Health Research Authority). Participants were provided with study information (including data protection). Consent was confirmed and no incentives were offered.

RESULTS

Participants

108 professionals responded (Table 1). Most had advanced/senior roles, with 4 holding joint appointments (typically hospital/hospice). Duplication occurred in 4 services. To avoid double counting, one response per service was included; possible because responses were largely consistent. However, all qualitative data was retained.

Response Rates

Respondents represented 108 perinatal services in 90 organisations across the UK and Ireland (Table 2). The response rate is estimated, as the precise number of eligible services was unknown and it was not possible to record how many invitations were distributed by recruiting organisations and subsequently cascaded. However, the aim was to target 242 services identified by the UKNC. Responses from 108 services therefore suggests an approximate response rate of 45% (acknowledging that some responses may have been external to the collaborative); highest for children's hospices and lowest for maternity services and fetal medicine centres (Supplementary Box A).

What was being implemented?

Respondents were asked to rate the level of PnACP implementation by selecting the category that best described their organisational approach. This revealed wide variation across all service types (Supplementary Table B – showing implementation levels for maternity, neonatal and palliative care services).

Taken as a whole, 9% of services reported an *innovative* level of implementation, with well-established policies and practices for PnACP that were informing regional or national practice. Indeed, analysis of the qualitative data revealed that these services had been instrumental in developing PnACP in ways that were endorsed by regional networks and/or adopted elsewhere. Most however, reported themselves to be users, rather than developers, of PnACP. This included 22% of services that reported *fully embedded* PnACP

(defined as having policies and practices that are integrated across the organisation and routinely used by relevant staff) and 37% with *partially embedded* PnACP (meaning policy and practices are evident, but approaches may vary within an organisation or be used inconsistently). In contrast, almost a third of services reported no policies or agreed practices for PnACP, and while 18% said they were in the process of developing these, 14% reported their implementation as *unguided*.

Data regarding roles were available for 99 (91%) services. The majority (80%) described themselves as *making* PnACPs (i.e. discussing, agreeing and recording plans) with parents. The remaining 20% supported others to make plans and/or acted upon plans made elsewhere.

Of those making plans, 66% used a standardised pro-forma. Most shared them or described their content; with 13 separate plans identified. They were broadly categorised as (i) general advance care plans and (ii) specific advance care plans that focused on emergency care, birth plans or end of life (Box 1). Content analysis showed they had overlapping features (e.g. essential medical details, resuscitation/emergency care plans, consideration of parent wishes), but varied in their labels, development, purpose, format, content and use. This raises potentially problematic issues. Definition, understanding and operationalisation of PnACP varied within and across settings. Nomenclature was inconsistent, even in relation to the same documents. For example, the Child and Young Person's Advance Care Plan [28] was referred to by 4 alternative names. It was also evident that Pro-formas were not always sufficient to cover care pathways, with different documents combined to reflect different aspects of care planning (e.g. resuscitation and broader parent wishes) or changes in circumstances (e.g. an antenatal ACP replaced/augmented with a NICU ACP); but with substantial overlap and duplication. Version control was also an issue, with some participants sending outdated pro-forma. The quality and depth of information also varied. For example, a bereavement section could require a detailed plan or just a tick box to indicate that parents had contact details for the unit counsellor. Finally, while some respondents clearly understood how their pro-forma linked to wider palliative care pathways or supporting resources, others did not.

Services not using pro-forma (n=27, 34%) most frequently recorded decisions made with parents in clinic letters, electronic patient records, parent letters and hand-held maternity notes. This was more common in neonatal and maternity services, compared to palliative care.

These diverse understandings and commitments to PnACP were underscored in the qualitative data. Many services described how they had re-organised working practices to include PnACP; believing it to be 'good practice' and associated with beneficial outcomes for babies, parents and staff. [Supplementary Quote: 1]

Services described many practices designed to support effective PnACP, including: regular multi-disciplinary/-agency meetings; development of new collaborative relationships; use of link/joint posts to support co-ordination across settings; involvement of specific personnel to support parent distress and decision-making (e.g. bereavement midwives, psychologists); activities to promote, model and teach PnACP practices within and across settings; offering premises to allow PnACP to occur in non-clinical spaces; contribution to service development working groups. [Supplementary Quote: 2]

However, some respondents were less convinced about the value of PnACP or were finding it hard to adopt new ways of working. They explained how policies for PnACP did not necessarily translate into practice-based guidance or suggested that pro-forma just formalised existing practices or encouraged 'tick box' working.

Understanding variations in practice through Normalisation Process Theory (NPT)

The data were also examined through NPT (Table 3) to understand service variation and the potential for PnACP to become routinised. This showed that PnACP has been driven by distributed networks of enthusiasts. Indeed, 10 of the 13 PnACP pro-forma were developed by professional or clinical networks who pooled expertise to create a vision for PnACP; often within wider care pathways (Box 1). However, different

groups produced different approaches, shaped by the embedded and accepted practices of their disciplines and settings. This has resulted in diverse understandings of PnACP and tensions about how PnACP should be integrated into daily work or shared across services. [Supplementary Quote: 3]

PnACP has also depended on 'special interest' champions who have helped services adopt these regional approaches or independently developed service-specific approaches. While some services legitimised this, by making PnACP an explicit part of an individual's role, it appears that much of this work has happened within existing working structures, and not easily prioritised. [Supplementary Quote: 4]

Involvement in PnACP was also associated with particular mind-sets, skill sets or roles. PnACP could therefore be considered niche; thereby dependent on a few individuals and inevitably limiting access to PnACP and its spread through organisations. Indeed, 37% of services reported that PnACP was used inconsistently within their organisation (partially embedded) and comparison of services co-located within the same organisation (e.g., a NICU and palliative care team) showed that services are often working in a culture of silos.

Despite the observed challenges, most favoured a formalised approach and were motivated to invest in new sets of practices; sustained by beliefs that they were driving-up standards in care. For instance, 92% of services using formal PnACP forms/templates to record plans believed they had 'much' or 'somewhat' improved their advance care planning. However, it was suggested that PnACP could be improved further by having 'a central set of policies' and a 'standardised pathway' to avoid 'every unit producing their own' with 'differences in care depending on consultant [sic]'. Indeed, it was evident that current models and resources for PnACP were considered laudable, but complex and 'too long-winded' to implement in perinatal settings due to clinical uncertainty, time-critical decision-making, high levels of parent distress, rapidly evolving situations, limited resources and fragmented healthcare systems – exacerbated by COVID-19.

[Supplementary Quote: 5]

Comments for improvement therefore focused on closing the practice-theory gap, with calls for more guidance, training, infrastructure and resources to apply the idealised principles of PnACP to real-life situations. Indeed, a wide range of support needs were reported (Table 4).

Discussion

To our knowledge, this is the first study to examine implementation of PnACP across perinatal care services. Consistent with studies in paediatric settings, the findings show that many services have engaged positively with advance care planning, but have unmet support needs regarding shared decision-making and collaborative working [19,29]. However, they also reveal additional challenges, related to the high uncertainty, short window for decision-making and liminal status of babies (situated at the boundaries of birth, services and care goals). The findings also show how different groups have developed PnACP; resulting in varied progress and understandings. Indeed, while some services have developed innovative practices for PnACP, this expertise and good practice is not always visible, shared or translated. Additional work is therefore necessary to tackle unwanted healthcare variations in PnACP; reflecting wider calls for maternity and neonatal services to be more equitable and knowledge-enabled [30-32].

The findings suggest that important steps will include clarifying the goals and intended outcomes for PnACP at different parts of the perinatal pathway, and identifying the most effective practice and service models to achieve these. This also involves understanding what variation is warranted (to adapt to local context) and unwarranted (health inequalities). Indeed, this study suggests that PnACP may benefit from a more unified approach, with shared policies, strategies and resources for practical implementation. Current approaches are valued, but some aspects are uniquely challenging in perinatal settings and can diminish motivation. This may reflect that some models for PnACP have been derived from paediatric palliative care. While these have advanced PnACP, there is increasing recognition that context matters. For example, the Child and Young Person's Advance Care Plan [28] has been recently revised to include an ante-natal form. Developed by a

wide reference group – this includes information to support multiple aspects of care during the ante-natal and “at birth” periods, and can be extended into infancy/childhood without having to introduce another advance care plan to the family. As such, it addresses many issues identified in this study. However, it will be important to continue building the evidence base from within perinatal care to ensure that future developments are feasible and effective. This includes evidence to guide shared decision-making in the context of high parental distress, uncertainty and short time-frames; in ways that improve transparency and outcomes, without increasing parent and staff burden. In the meantime, this study provides direction for core criteria and guidance in PnACP (Box 2).

The King’s Fund also suggests that care providers may need ‘harder-edged, locally focused incentives to encourage action to deal with unwarranted variation’ (p.8) [33]. PnACP has largely developed through the commitment and goodwill of enthusiasts who have developed informal cultures of good practice.

Implementation of PnACP therefore depends on local context, which is unlikely to provide the resources, incentives or accountability to encourage routine implementation, until considered essential or mandatory. Indeed, insufficient service resources were cited as a major barrier, particularly having a skilled workforce to develop and implement PnACP. The importance of this has been recognised by the Children’s Palliative Care Education Standard Framework [34], which has been expanded to include advance care planning, including PnACP. Unfortunately, transforming the workforce will also require investment to address current shortages in medical, nursing and specialist staff to support families [35].

While this study has contributed new insights, several limitations should be considered. The response rate was suboptimal, with maternity services under-represented. While this may reflect the challenges of conducting a survey during a pandemic, these services may have been reluctant to participate because of lower involvement in PnACP. Differential interpretations of PnACP may also have affected the responses. For instance, a minority of services reported not having a PnACP pro-forma, because they used plans designed for children, rather than specific to babies. Conversely, others stated they used PnACP resources, but provided no evidence. Some responses also depended on subjective judgement. For example, examination

of duplicated responses, showed that members of the same team sometimes could be inconsistent in their ratings of implementation level. These differences were small, but suggest that organisations need support to accurately assess implementation of PnACP. Developing benchmarking tools may be useful.

Despite limitations, the findings derived from wide-ranging services, across the UK and Ireland and at different stages of implementation; providing a broad range of contexts. It also demonstrates a wealth of expertise within perinatal care and a network of enthusiasts who understand the value of PnACP. This suggests that the potential for normalisation is high, as long as work can be done to create a shared vision for PnACP and increase participation among a wider set of professionals who care for babies with life-limiting conditions.

What is already known on this topic

- Perinatal advance care planning (PnACP) is advocated for babies with a life-limiting or life-threatening condition and can be made during pregnancy or after birth.
- Earlier recognition of end-of-life is associated with less suffering in babies and better outcomes for parents.
- Little is known about the use of PnACP in perinatal care settings or the factors that shape implementation.

What this study adds

- The findings provide a detailed picture of PnACP, revealing the views and practices of professionals working in different perinatal care settings and geographical regions.
- Considerable work has been undertaken to develop PnACP, but there is wide variation in conceptualisation, uptake and implementation.
- Normalisation Process Theory provides a useful way to examine implementation of PnACP by revealing the individual and collective work that has influenced progress.

How this study might affect research, practice or policy

- The findings indicate a growing use of PnACP, but more research is required to identify the optimal model/s for PnACP.
- The findings suggest a need for policy and practices that unify understanding and approaches across settings, and offer information that will support improvement strategies.
- The findings highlight several of workforce priorities, including support for professionals to improve their competencies in PnACP and systems to improve collaborative working across services.

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Contributorship statement

KLS and JS conceived the study. KLS, JS, CC, AW and MK made substantial contributions to the research design. Data collection and analysis was led by KLS, but authors contributed to the acquisition and interpretation of data. KLS wrote the first draft of the paper, which was critically reviewed and revised by all authors. All authors approved the final version and are responsible for it.

Table 1: Participant characteristics

Profession	Count (%)
Doctors:	65 (60.1)
- Consultant Paediatrician <i>Special interest – where indicated in fetal (n=1); perinatal (n=1), neonatal (n=5), palliative care (n=6)</i>	31 (28.7)
- Consultant Neonatologist	24 (22.2)
- Consultant in Paediatric Palliative Care	5 (4.6)
- Consultant Obstetrician & Gynaecologist/Fetal Medicine <i>Includes 1 Specialist Registrar</i>	4 (3.5)
- Consultant Cardiologist	1 (0.9)
- General Practitioner (Hospice)	1 (0.9)
Nurses (Neonatal and Paediatric):	35 (32.4)
- Matron/Senior Nurse Manager	4 (3.7)
- Sister/Ward Manager	7 (6.5)
- Nurse Consultant/Advanced Nurse Practitioner	5 (4.6)
- Clinical Nurse Specialist	11 (10.2)
- Specialist Bereavement Nurse	1 (0.9)
- Community Children's Nurse/Diana Nurse	4 (3.7)
- Staff Nurse/Nurse Practitioner	3 (2.8)
Midwives:	7 (6.5)
- Head of Midwifery	1 (0.9)
- Midwife Manager	1 (0.9)
- Consultant Midwife	1 (0.9)
- Specialist Bereavement Midwife	4 (3.7)
Other	1 (0.9)
- Head of Hospice Care – profession unspecified	1 (0.9)
Total	108 (100.0)

Table 2. Service Characteristics

Type of Service	Count (%)
Maternity Services:	12 (11.1)
- Obstetric Unit	8 (7.4)
- Midwifery Unit	1 (0.9)
- Fetal Medicine	2 (1.9)
- Fetal Specialists (e.g. cardiology)	1 (0.9)
Neonatal Services:	54 (50.0)
- Special Care Baby Units	5 (4.6)
- Local Neonatal Unit	23 (21.3)
- Neonatal Intensive Care Units	25 (23.1)
- Neonatal Surgery	1 (0.9)
Palliative and Bereavement Care Services:	39 (36.1)
- Hospital services	5 (4.6)
- Community service	9 (8.3)
- Joint hospital & community services	4 (3.7)
- Children's Hospices	21 (19.4)
Other	3 (2.8)
- Tissue donation service	1 (0.9)
- NHS Trusts/Health Boards	2 (1.8)
Total	108 (100.0)

Box 1: Summary of P-ACP documents and templates shared with research team

GENERAL ACP DOCUMENTS AND TEMPLATES

Typically applicable to all child age groups (babies, children and young people) and designed for use in a range of care settings (hospital, hospice, home) and by the emergency services. Not developed specifically for perinatal settings, but most make explicit statements that they can be used antenatally. All are family-held documents; although one is a template designed to help professionals produce a family-held document. Include plans for clinical deterioration, emergency events and end of life, with a focus on wishes during life and at end of life. Most developed at a national or regional level and publically available. Generally consist of a booklet containing several pages of structured sections for completion with families. Most direct the original copy to be held by parents, with copies distributed to services that may be called upon to implement it. Some are supported with policy documents, guidance for use, and family information leaflets.

- *CYPACP: Child and Young Person's Advance Care Plan* [[Available here](#)]
- *PAC-Plan: Paediatric Advanced Care Plan* [[Available here](#)]
- *My Anticipatory Care Plan* [[Available here](#)]
- *Child and Family Wishes: Discussion Record* [[Available here](#)]
- *Advance Care Plan.* [[Available here](#)]
- *Child and Young Person's Advance Care Plan Locally developed (Children's Hospice), not publically available*

SPECIFIC ADVANCE CARE PLANS

- a. **Emergency health care plans** - Record preferences for clinical care and treatment in emergency situations. These include a nationally developed plan for use in all age groups, including adults, across settings (e.g. ReSPECT) and a regional plan for use in a specific perinatal contexts (i.e. NICU). Both are family-held documents and while their focus is on clinical decision-making (i.e. resuscitation), they do include non-clinical aspects such place of care, spiritual needs etc..
 - *ReSPECT: Recommended Summary Plan for Emergency Care and Treatment.* [[Available here](#)]
 - *NICU Personal Resuscitation Plan and Emergency Healthcare Plan Not known if publically available*
- b. **Birth plans & early neonatal care** - Most are developed by regional clinical networks, are documents for staff use – filed in medical records. Record decisions about place of birth, mode of delivery, early neonatal management and place of care. Include information about parental needs and wishes (e.g. memory making, spiritual needs), but are primarily medically focused (e.g. medication, monitoring resuscitation, comfort care).
 - *ICCP: Integrated Comfort Care Pathway – Newborns* [[Available here](#)]
 - *Multidisciplinary antenatal assessment of infants with significant, complex, life threatening or life-limiting, congenital anomalies.* [[Available here](#)]
 - *Special Baby Plan. Local (NHS Trust) Family held-document. Not known to be publically available.*
- c. **End of life care** - Regional (clinical network) documents to record preferred places of care (e.g. hospice or home), clinical care of the mother (e.g. milk suppression) and bereavement care. These tend to be family-held and wide ranging; documenting decisions regarding medical care, memory making, discharge and transfer to alternative places of care, care after death, post-death documentation
 - *North West Neonatal Palliative Care Plan for Babies Cared for on a Neonatal Unit* [[Available here](#)]
 - *North West Neonatal Palliative Care Plan for Home and Hospice* [[Available here](#)]

Table 3: Key findings organised within NPT²⁰

<p>Coherence: Successful implementation of new ways of working requires that people can make sense of it and its associated practices (coherence). This involves individual and collective work to understand how it differs from previous practices (differentiation), what it means for team working (communal specification), what it means for individual roles (individual specification) and its value (internalisation).</p>			
<p>Differentiation</p> <p>Most differentiated PnACP favourably, compared to previous ways of working.</p> <p>PnACP considered to involve sets of practice that differ from normal working e.g. additional care plans, specialists, places of care, parental support.</p> <p>Varied conceptualisations of PnACP, including the purposes, contexts in which they apply, practices, processes.</p>	<p>Communal specification</p> <p>Belief that PnACP is relevant to diverse babies/parents and suitable for use in many pre and post-natal settings.</p> <p>Belief that PnACP requires input from a wide range of disciplines.</p> <p>Belief that PnACP can be initiated in maternity, neonatal and palliative care settings – but less agreement about who should lead or take ownership of the process.</p> <p>Beliefs that PnACP should follow the baby, but plans do not always traverse across boundaries.</p>	<p>Individual specification</p> <p>Belief that many professionals working in maternity, neonatal and palliative care can (and do) contribute positively to PnACP.</p> <p>Belief that involvement in PnACP offers opportunities for personal development and increased job satisfaction.</p> <p>Understanding and distribution of roles does not appear to be underpinned by formal allocation processes.</p>	<p>Internalisation</p> <p>Considered an important mechanism to support high quality care.</p> <p>Variable investment in PnACP.</p> <p>Most, but not all, believe formalised processes and pro-formas are worthwhile.</p> <p>PnACP described as having real or anticipated benefits for babies, parents and care providers.</p>
<p>Cognitive participation: While sense-making is important, successful implementation also depends on relational work to develop and sustain practices around new ways of working. This needs key people to drive it forward (initiation), bring in and organise others to be active participants (enrolment), a shared belief that it is right for them to be involved (legitimation) and determination to keep it going (activation).</p>			
<p>Initiation</p> <p>PnACP driven by networks of enthusiasts who have provided an informal knowledge economy.</p> <p>Significant work done by regional/national clinical groups who have pooled expertise to develop a vision for PnACP and resources.</p> <p>Initiation may be harder in services less connected to these networks and where there is no local/regional leadership.</p>	<p>Enrolment</p> <p>Service-level engagement driven by special interest champions.</p> <p>Some services have reorganised individual and group relationships to incorporate PnACP, including designated points of contact or joint posts across neighbouring settings to facilitate enrolment and unify approaches.</p> <p>Others are finding it challenging to reorganise existing ways of working.</p>	<p>Legitimation</p> <p>Collaborative working considered important in PnACP, but also a major barrier.</p> <p>Many services are reaching out to others to highlight how they can contribute to PnACP and demonstrating a willingness to work collaboratively.</p> <p>Some services feel ill equipped to make plans with families and ‘outsource’ this work to other professionals or services.</p> <p>Some services feel well equipped to support PnACP, but poorly integrated in perinatal care</p>	<p>Activation</p> <p>Many services have developed or adopted care pathways that include PnACP and practice-based resources.</p> <p>Many working practices that sustain PnACP have been identified e.g. early involvement of specialist services.</p> <p>PnACP not always prioritised or formalised in services and is dependent on small number of staff.</p> <p>Many services appear to be working in a culture of silos.</p> <p>Local/regional leadership for PnACP is lack in many areas.</p>

<p>Collective action is the operational work that people do, individually and collectively, to enact new way of working. It involves working with others and objects to perform new practices (interactional workability), building accountability and confidence in these (relational integration), distributing the work appropriately (skill set workability) and the allocation of resources (contextual integration)</p>			
<p>Interactional workability</p> <p>Frameworks, guidance and resources for PnACP have been developed for use in care settings. This includes some educational materials to support operationalisation.</p> <p>Many participants described dissonance between PnACP guidance and the practical realities of working in perinatal settings.</p>	<p>Relational integration</p> <p>Some services have made firm commitments to PnACP, and have taken steps to clarify their approach.</p> <p>Some have designated members of staff to act as key contacts for PnACP. These act as advocates and knowledge brokers within and between services, and provide opportunities to see the benefits of collaborative working (e.g. through joint meetings and training opportunities, pathways that highlight the value of their involvement, developing shared resources with joint ownership)</p> <p>Many factors can contribute to low trust in the PNACP and the work of others.</p>	<p>Skill set workability</p> <p>Many disciplines and settings are considered important in the construction and enactment of PnACP; including parents.</p> <p>Recognition that effective PnACP requires adaptation and re-negotiation of roles. But appropriate division of tasks is an area of uncertainty and tension. Work often seen as requiring special mind-set or skillset. Thus, work can be allocated based on special interest or alignment to existing role-features. These people are highly motivated to develop their skills, but risks making PnACP the responsibility of limited staff.</p> <p>Existing work routines are not always conducive to developing new roles.</p>	<p>Interactional workability</p> <p>PnACP seems to have developed through the commitment and goodwill of professionals and organisations.</p> <p>There are limited resources or hard-edged incentives to support or encourage action to implement PnACP.</p> <p>Many barriers to PnACP are described, including lack of staff time, lack of specialist staff, information-sharing systems.</p>
<p>Reflexive monitoring is the appraisal work that people engage in to understand if a new set of practices is worthwhile. This involves obtaining information to evaluate new practices (systemisation), working together to assess their impact (communal appraisal), personal assessments about how they will affect their work and working context (individual appraisal) and work to modify practices (reconfiguration).</p>			
<p>Systemisation</p> <p>Evidence of benefit is major motivator for PnACP.</p> <p>Few purposeful activities to evaluate PnACP are reported.</p> <p>Few formal strategies to ensure knowledge transfer are reported.</p> <p>Impact of PnACP appeared to be mainly assessed experientially</p>	<p>Communal appraisal</p> <p>Some teams, services and networks 'reflect on' and 'share' their collective learning.</p> <p>Participation in this study suggests many services, organisations and individuals recognise knowledge gaps in PnACP and are willing to contribute to the evidence base.</p>	<p>Individual appraisal</p> <p>PnACP described as conferring wide-ranging benefits, and associated with better outcomes during and beyond care (including workforce benefits e.g. reduced moral distress)</p> <p>PnACP can be a source of distress and dissatisfaction when used in contexts where there is insufficient knowledge, skill and competency</p> <p>PnACP described as adding to workload Respondents rate themselves and other staff to have unmet training and support needs</p>	<p>Reconfiguration</p> <p>Many services are actively engaged in improvement cycles (i.e. developing approaches, applying them in work settings, modifying them to address observed inadequacies).</p> <p>Overall, the benefits appear to outweigh the risks and effort – and support continued investment</p> <p>Implementation challenges may reflect that some approaches to PnACP have been adapted from paediatric palliative care. May need some reconfiguration to reflect perinatal context</p>

Table 4: Support needs (n=88)

	Count (%)
Collaborative working	32 (36.4)
Planning for clinical needs (e.g. birth plans, resuscitation, deterioration)	31 (35.2)
Systems/technologies to record, share and flag plans	31(35.2)
Planning for non-medical needs (e.g. cultural, psychosocial, memory making)	29 (32.9)
Planning for end of life and bereavement care	24 (27.3)
Shared decision-making	23 (26.1)
Workforce skill set	23 (26.1)
Pathways & eligibility criteria	22 (25.0)
Funding and resources	21 (23.9)
Keeping plans relevant and up-to-date	15 (17.0)
Leadership and organisational support	9 (10.2)

Box 2: Core components of PnACP

CONTEXT

- Included within a wider perinatal palliative care policy/pathway
- Suitable for use across care settings and regions, including emergency services.
- Suitable for use throughout the perinatal care pathway from diagnosis/recognition (e.g. from antenatal diagnosis onwards) – through to bereavement, if needed. May occasionally be discussed earlier e.g. new pregnancy after previous baby loss.
- Suitable for use in a parallel planning approach – which can be extended for use in neonatal/paediatrics without having to re-introduce another care plan to the family.

PLANS

- Plans should be focused on best interests of baby, with clear plans to support parents and wider family.
- Plans should facilitate and document shared decision-making – where parents have access to advice from current and potential care providers (including palliative care services).
- Plans should document medical, psychosocial, spiritual and cultural needs.
- Plans should include, or provide clear signposting to, other plans, such as specific birth plans.
- Plans should be a parent-held document – copied to all services that may be potentially involved in current and future care of baby, mother and family.
- Plans should be user-friendly and designed in ways that support accurate information. This includes sufficient detail and/or actions plans to make them meaningful to parents and offer clear direction for implementation.
- Plans should be practicable for documenting/use in all potential scenarios and time-scales (acknowledging that some parents will have weeks/months to consider and make a plan, and others will have hours/days).

USER GUIDANCE

- Parents need clear information about PnACP to understand its purpose, use, legal aspects and limitations. They also need support for completion, including adequate preparation and aftercare.
- Perinatal care providers need clear instructions to promote a shared understanding of PnACP and how these link to existing local and national policies and pathways.
- Healthcare professionals need support and training opportunities to know when and how to introduce plans to parents, how to promote engagement with them, and how to optimise completion.
- Healthcare staff need support to ensure plans are based on collaborative working, including clear guidance about the processes to share information and how to delineate, share or transfer roles and responsibilities.

ORGANISATIONS and WIDER STRUCTURES

- Healthcare commissioners should specify PnACP in planning perinatal care services.
- Perinatal care providers should have a policy for PnACP that sits within an integrated palliative care pathway.
- Perinatal care providers should offer PnACP to all parents whose baby is diagnosed with a life-limiting condition.
- Perinatal care providers should make sure that professionals have the skills and knowledge to undertake PnACP.

Supplementary Box. Estimated response rates

Maternity Services: 6.7% Fetal Medicine Centres plus 9 maternity services

Estimated (from the UK Neonatal Collaborative map) that 2 of the 30 fetal medicine centres responded, plus additional responses from 8 obstetric units, 1 midwifery unit and 1 fetal surgical speciality.

Neonatal services: 28.1%

Estimated (from the UK Neonatal Collaborative map) that there are approximately 192 neonatal service and responses were received from 12.8% (5/39) Special Care Baby Units, 27.9% (23/86) Local Neonatal Units, 42.6% (25/61) Neonatal Intensive Care Units and 16.7% (1/6) Neonatal Surgery Units.

Palliative Care services: 50% children's hospice providers, plus 19 response from palliative care services

Estimated (from Together for Short Lives Directory) that 51 children's hospices or 'hospice at home' services offer perinatal services in the UK and Ireland; delivered through 38 regionally-based organisations. This gives a response rate of 21 (41.2%) hospices, representing 19 (50.0%) organisations. A further 18 responses were provided by hospital and/or community palliative care services.

Supplementary Table: Level of implementation

	Innovative	Fully embedded	Partially embedded	Developing	Unguided
All Services (n=108)	10 (9.3)	24 (22.2)	40 (37.0)	19 (17.6)	15 (14.7)
Maternity Services (n=12):	0 (0.0)	3 (25.0)	5 (41.7)	1 (8.3)	3 (25.0)
Neonatal Services (n=54)	5 (9.3)	15 (27.8)	21 (38.9)	6 (11.1)	7 (13.0)
Palliative & Bereavement Care Services (n=39)	5 (12.8)	5 (12.8)	13 (33.3)	12 (30.8)	4 (10.3)
Other (n=3)	0 (0.0)	1 (33.3)	1 (33.3)	0 (0.0)	1 (33.3)

Innovative: Well-established policies and practices - that are informing regional/national strategies

Fully embedded: Policies and practices are integrated across the organisation and used routinely by relevant staff

Partially embedded: Policies and practices are evident, but use is variable or inconsistent across the organisation

Developing: Policies and practices are currently being developed

Unguided: There are no policies for perinatal advance care planning

Supplementary Quotes

1	<i>It helps us to discuss honestly the issues related to care and management as parents are well informed. - perinatal ACP in place helps the local team to arrange palliative care or discussion about end of life care easier. - also helps other nursing colleagues to support the decision without much emotional affect or ethical dilemma. [Local Neonatal Unit]</i>
2	<i>We have a weekly MDT involving fetal medicine, NNU, fetal cardiology and geneticists which with remote working local paediatricians and obstetricians can also join. Cases in which advanced planning is beneficial are identified and plans are then taken forward by the relevant teams (usually joint fetal medicine and neonatologists but others may be involved, especially the local hospices) [Fetal Cardiology]</i>
3	<i>Our team's biggest challenge in perinatal care is not having any warning about the potential babies - ie no antenatal referrals. Referrals usually occur as the 'baby hasn't died yet'. This means our teams are entering into a very stressed situation without prior meeting/relationship building with families. Antenatal meeting would help to 'parallel plan' - what are the options if the baby lives on? [Children's Hospice]</i>
4	<i>NICU teams are unfamiliar with CYACP and so feel awkward having these discussions and with the completion. We would like to do more link work/education for NICU teams but staff shortages and COVID combined have basically put a stop to this this year. [Community Palliative Care]</i>
5	<i>Sometimes when death is expected immediately peri delivery the ACP is far too long winded for this purpose [Neonatal Intensive Care Unit]</i>