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A care pathway for emotional and informational support in donor-conceived people

Petra Sofia Mendonça Fernandes

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Faculdade de Psicologia e de Ciências da Educação

A CARE PATHWAY FOR EMOTIONAL AND INFORMATIONAL SUPPORT IN DONOR-CONCEIVED PEOPLE

Petra Sofia Mendonça Fernandes
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RESUMO

A conceção com recurso a doação de gâmetas tem implicações ao longo da vida, com necessidades de informação e apoio que podem variar entre etapas de desenvolvimento e acontecimentos de vida. Contudo, o apoio disponível permanece fragmentado, com orientações limitadas sobre a sua organização. Este estudo teve como objetivo desenvolver um Guia de Cuidados centrado na pessoa, informado pelas perspetivas dos principais intervenientes. Foram realizados 6 grupos focais online com 30 participantes residentes em 12 países: 10 pessoas concebidas por doação, 8 profissionais de saúde, 9 pais de pessoas concebidas por doação e 3 dadores. Os participantes discutiram uma versão preliminar do Guia de Cuidados, abordando as necessidades de apoio, quando e como este deveria ser disponibilizado e as condições necessárias à implementação do mesmo. As discussões foram transcritas *verbatim* e analisadas qualitativamente para refinar o percurso. Os resultados incidiram sobre a descoberta das circunstâncias da conceção, informação fiável e atualizada, apoio psicológico, jurídico e genético, apoio de pares e da comunidade, e acesso às origens genéticas e ao contacto. Os participantes salientaram necessidades variáveis ao longo da vida e do desenvolvimento. Destacaram ainda competências profissionais específicas na conceção com recurso a dador, coordenação independente e garantia da qualidade. O Guia de Cuidados fornece uma estrutura organizada para integrar informação e apoio profissional e comunitário, reconhecendo as necessidades distintas e em evolução das pessoas concebidas por doação, dos pais e dos dadores.

Palavras-chave: conceção com recurso a dador, pessoas concebidas por dador, Guia de Cuidados, apoio psicossocial, investigação qualitativa

ABSTRACT

Donor conception has lifelong implications, with information and support needs that may vary across developmental stages and life events. However, care remains fragmented, with limited guidance on its organisation. This study aimed to develop a person-centred Care Pathway informed by the perspectives of key stakeholders. Six online focus groups were conducted with 30 participants residing in 12 countries: 10 donor-conceived people, 8 healthcare professionals, 9 parents of donor-conceived people and 3 donors. Participants discussed a preliminary version of the Care Pathway, addressing support needs, the timing and delivery of care, and considerations for implementation. Discussions were transcribed verbatim and analysed qualitatively to refine the pathway. Findings centred on disclosure and discovery of conception circumstances, reliable and updated information, psychological, legal and genetic support, peer and community support, and access to genetic origins and contact. Participants emphasised changing needs across the life course, follow-up opportunities linked to development and opportunities to re-enter care. They also highlighted professional competence specific to donor conception, independent coordination and quality assurance. The Care Pathway provides an organised framework for integrating information, and professional and community support, recognising the distinct and evolving needs of donor-conceived people, parents and donors.

Keywords: donor conception, donor-conceived people, care pathway, psychosocial support, qualitative research

INTRODUCTION

Over recent decades, the use of Assisted Reproductive Technologies (ART) has increased substantially, partly as a result of delayed childbearing and the consequent rise in age-related fertility difficulties in many developed countries (Jadva, 2026). ART encompasses a broad range of medical procedures designed to assist individuals and couples in achieving pregnancy and has become an important route to parenthood, not only for people experiencing infertility, but also for LGBTQAI+ individuals and families.

ART procedures may involve either the intended parents' own reproductive material or donated gametes or embryos. The use of donated reproductive material may be indicated for several reasons, including severe male-factor infertility, premature ovarian insufficiency or loss of ovarian function, the risk of transmitting a genetic condition, as well as circumstances in which parenthood is pursued without access to both male and female gametes, such as by same-sex couples or single intended mothers (Uppal et al., 2025). Donor conception may involve sperm donation, oocyte donation, the use of both donated sperm and oocytes, or embryo donation. Individuals conceived through these forms of third-party reproduction are commonly referred to as donor-conceived people (DCP).

For a long time, donor anonymity was an expectation of donor conception, but with the rise of direct-to-consumer genetic testing, the debate surrounding the ethics of separating DCP from their genetic information has been increasing (Darroch & Smith, 2021). DNA profiling and genealogical research now enable individuals to investigate their genetic ancestry and identify biological relatives, including donors and donor siblings, outside formal donor registries (Zadeh, 2024). Additionally, medical professionals commonly advised parents to withhold information regarding donation to DCP until the mid-1980s (Shepard et al., 2022), leading to some donor-conceived people growing up unaware of their conception circumstances and finding out about their misattributed paternity or unexpected relatives through direct-to-consumer DNA testing.

The shift toward identity-release or open-identity donation, in which recipients have access to non-identifying donor information while donor-conceived people may obtain the donor's identity once they reach a specified age, has begun in several countries (Skoog Svanberg et al., 2020). The Parliamentary Assembly of the Council of Europe suggests balancing the rights of parents, donors and children, by recommending that donor anonymity be waived for all future gamete donations in member States, proposing that DCP have access to identifying donor information upon reaching their 16th or 18th birthday (Parliamentary

Assembly, 2019). Countries such as Sweden, Austria, Victoria (Australia), Switzerland, the Netherlands, Western Australia (Australia), Norway, United Kingdom, New Zealand, Finland, New South Wales (Australia), Portugal, Germany and Ireland, have already adopted open-identity systems (Indekeu et al., 2021).

Disclosure

As donor conception becomes more visible, there is growing recognition that donor-conceived people may encounter distinct psychological, emotional, and social experiences and considerations across the life course (Zweifel, 2015). These individuals are increasingly vocal in asserting their rights to information about their genetic and biographical origins (Parliamentary Assembly, 2019). While the shift toward identity-release and open-identity donation reflects this change, many DCP still face challenges. Notably, having access to donor information does not always coincide with disclosure. Some parents may possess identifying details but still choose not to inform the child, and studies vary on how a donor's known or anonymous status influences disclosure decisions (Klock & Greenfeld, 2004). More recent research suggests that disclosure decisions are influenced by multiple interacting personal, familial, and contextual factors, highlighting the complexity of this process within donor-conceived families (Duff & Goedeke, 2024).

Research suggests that the timing and circumstances of disclosure can influence how donor-conceived people experience and understand their donor-conceived status (Duff & Goedeke, 2024). Understanding of biological heritance begins early in childhood development, and children who are informed of their donor-conceived status at an early age may have greater opportunity to gradually integrate this information into their self-concept (Ilioi et al., 2017). In contrast, late or unexpected disclosure may require individuals to integrate previously unknown information about their genetic origins into an already established understanding of themselves and their family (Shepard et al., 2022). The circumstances surrounding late disclosure or unexpected discovery can be associated with psychological distress and challenges to identity, with some individuals reporting feelings of sadness, anger, betrayal and grief (Shepard et al., 2022). Some DCP describe the shock of disclosure as evoking feelings of losing their familiar world and the need to reevaluate their identity and how they fit in the world (Turner & Coyle, 2000). A recent systematic review similarly identified that DCP experience feelings of

deception, identity confusion, and a lack of support when attempting to access information about their origins (Talbot et al., 2024).

Search for information

While the decision to disclose donor conception often rests with parents or external influences, the pursuit of donor-related information or contact is usually driven by the donor-conceived individuals themselves. A systematic review of 49 studies explored the perspectives of DCP, parents, and donors on the factors influencing the search for information and/or contact with donor-related individuals (Indekeu et al., 2021). Among DCP, motivations included curiosity, a desire to understand the origins of their characteristics and abilities, and a wish to gain a deeper understanding of their identity. Some also expressed an interest in establishing relationships with donor-related individuals and potentially extending their family connections.

Research also suggests that DCP who experience late disclosure, in addition to reporting more negative emotions, are generally more likely to seek information about their donor (Lampic et al., 2022), including information about their genetic heritage and medical background, and to establish contact with the donor and the donor's family. Access to genetic and medical information may also motivate information-seeking among DCP. In some cases, questions regarding genetic origins and medical history have led parents to seek information or contact with donors on behalf of their donor-conceived children (Duff & Goedeke, 2025). Information-seeking in donor conception may extend beyond identifying the donor, encompassing questions related to genetic origins, identity, medical information, and potential relationships with donor-related individuals (Indekeu et al., 2021).

Despite growing recognition of the longer-term implications of donor conception, access to psychosocial support remains inconsistent. Post-donation support is rarely formally established and varies considerably across jurisdictions, with limited provision of specialised and publicly funded services (Goedeke et al., 2026). This variability raises questions regarding how informational and psychosocial support can be organised and provided across different stages of the donor-conception experience. A care pathway may provide a useful framework for addressing this fragmentation by clarifying routes of access and coordinating relevant resources over time, while remaining responsive to diverse experiences and circumstances.

Care Pathway

Care Pathways, also referred to as clinical pathways, critical pathways, or integrated care pathways, are used to organise care processes and make patient-focused care operational (Vanhaecht et al., 2010). This concept was introduced and applied to healthcare settings as a means of organizing processes involving multiple professionals and interventions, with the aim of improving coordination, consistency, and outcomes in patient care (G. Schrijvers et al., 2012).

The use of Care Pathways may include shortening the duration of care processes, increasing coherence between the professionals and services involved, reducing the risk of errors and costs, and potentially increasing professional satisfaction through clearly defined and coordinated frameworks (G. Schrijvers et al., 2012). However, greater standardisation may also contribute to the dehumanisation of care, reduce patient choice and diversity in professional practice, and, under some circumstances, negatively affect communication and professional satisfaction. These limitations reinforce the importance of continuously evaluating and improving Care Pathways rather than considering them static models of care (Vanhaecht et al., 2010).

Care Pathways have been applied in areas that imply a more patient-focused care and a more complex treatment, that aims to improve mental health and not just organize and standardize care, including schizophrenia (Jones & Kamath, 1998), dementia (Samsi & Manthorpe, 2014) and for children and adolescents with gender dysphoria (Taylor et al., 2024). In dementia care, for example, Care Pathways have been considered in the context of an uncertain and unpredictable trajectory, in which individuals may navigate different services and professionals according to their needs, illustrating how Care Pathways may be used beyond a single, linear clinical intervention (Samsi & Manthorpe, 2014).

In the context of donor conception, donor-conceived people are not inherently patients and do not necessarily require professional support. However, informational and psychosocial support may become relevant at different points and under different circumstances, including disclosure, the search for information about genetic origins, and contact with donor-related individuals. At the same time, the availability and organisation of psychosocial support remain inconsistent across jurisdictions (Goedeke et al., 2026).

The present study

The present study aims to develop a person-centred Care Pathway for donor-conceived people by incorporating the perspectives of key stakeholders involved in donor conception, including DCP, parents, donors, and healthcare professionals. Specifically, the study seeks to identify stakeholders' perceived emotional and informational support needs, determine when and how support should be provided across the donor-conception journey and life course, and explore which professionals, services, or organisations should be involved in its provision and coordination.

METHOD

Design

This study was conducted within the MyGenesis project (Fundação para a Ciência e a Tecnologia, 2023.14465.PEX), which examines donor-conceived people's experiences of identity and their informational and psychosocial support needs. The present study contributed to the project by developing a care pathway with donor-conceived people and other stakeholders.

Consistent with the MRC guidance for complex interventions, which emphasises the articulation and iterative refinement of programme theory during intervention development (Craig et al., 2013), the design phase began with the development of an initial care pathway. This pathway provided a provisional theoretical framework for the organisation of informational and psychosocial resources for donor-conceived people (Figure 1). It was adapted from the model proposed by Tindall et al. (2023) and was intended to be explored and refined with key stakeholders.

The "point of disclosure" refers to the point at which an individual becomes aware of their donor-conceived status, either through parental disclosure or unexpected discovery. For individuals who have always known about their donor conception, this point represents the gradual development of an understanding of what being donor-conceived means. DCP may therefore enter this stage at different points across the life course, from childhood to adulthood.

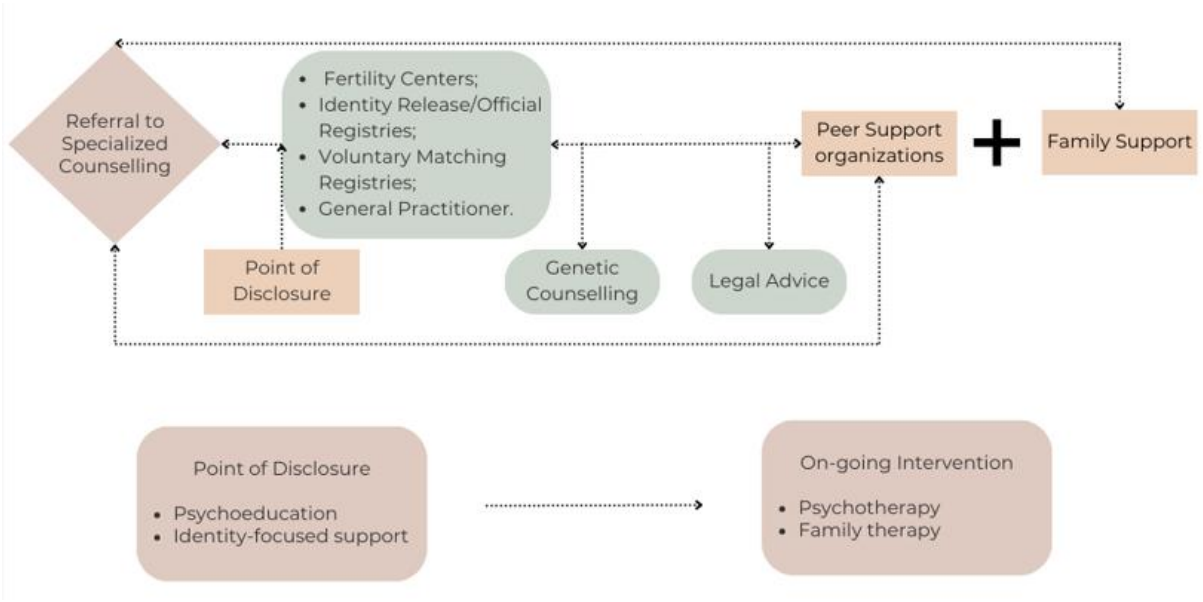
The pathway identifies potential sources of referral and support, including ART clinics and fertility centres, official identity-release registries, voluntary matching registries, and

general practitioners. These referral points may provide or facilitate access to psychological support, genetic counselling, and legal advice. Peer organisations and family support are also represented as potential sources of ongoing support.

The bottom section of the pathway represents potential forms of support across time. Around disclosure or discovery, these include psychoeducation and identity-related support, while subsequent support may include peer support and family-based psychological interventions. As a preliminary model, the pathway was intended to provide a basis for stakeholder discussion rather than to prescribe a fixed sequence of support.

Figure 1

Proposed Care Pathway



Procedure

The focus group discussion guide was developed alongside a preliminary care pathway adapted from the care pathway proposed by Tindall et al. (2023). The discussion guide was designed to explore stakeholders' perspectives on emotional and informational support associated with donor conception, the timing and continuity of support, the professionals and services considered appropriate for its provision, and potential barriers and facilitators to implementation. The study received ethical approval from the Ethics Committee of the Faculty

of Psychology and Educational Sciences of the University of Porto (Ref. 2025-10-01). Before participation, individuals received information about the aims and procedures of the study, the voluntary nature of participation, confidentiality and data handling, and their right to withdraw. Informed consent was obtained prior to participation.

The preliminary care pathway was presented to participants (Figure 1) and discussed using a semi-structured focus group guide (Appendix A). The guide included an initial reflection activity followed by questions exploring participants' views on the content and organisation of the pathway, including the types and timing of support, potential gaps, accessibility, delivery formats, and pathway navigation. Participants were also encouraged to identify elements they considered missing, unnecessary, or in need of modification.

A total of 6 online mixed-stakeholder focus groups were conducted between January and February 2026. Focus groups included participants from different stakeholder groups to promote discussion across both lived-experience and professional perspectives.

The sessions were conducted online via Zoom, facilitating participation across different geographical locations. Each focus group lasted approximately 60 minutes and included four to eight participants.

Participants

Participants represented four stakeholder groups involved in donor conception: donor-conceived people, parents of donor-conceived people, gamete donors, and healthcare professionals working in ART. All participants were required to be aged 18 years or older and fluent in English.

Participants were recruited through social media, donor-conceived organisations and scientific and professional networks. Recruitment aimed to include participants from different geographical and stakeholder backgrounds.

A total of 30 participants took part in the study, including 10 donor-conceived people, nine parents of donor-conceived people, three donors, and eight healthcare professionals. Participants resided in 12 countries: Argentina, Australia, Belgium, Denmark, Germany, Portugal, Spain, Sweden, Switzerland, Türkiye, the United Kingdom, and the United States.

A sociodemographic characterisation of the sample is presented in Table 1, including stakeholder group, estimated age group, gender, education level, employment status, and country of residence.

Table 1

Participant Characteristics by Stakeholder Group

Characteristic	DCP		Parents of DCP		Healthcare professionals		Donors		Overall	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Estimated age group										
21–30	4	40	1	11.1	0	0	2	66.7	7	23.3
31–40	1	10	1	11.1	2	25	0	0	4	13.3
41–50	3	30	7	77.8	2	25	0	0	12	40
51–60	2	20	0	0	1	12.5	1	33.3	4	13.3
≥61	0	0	0	0	3	37.5	0	0	3	10
Gender										
Female	8	80	9	100	8	100	2	66.7	27	90
Male	1	10	0	0	0	0	1	33.3	2	6.7
Prefer not to say	1	10	0	0	0	0	0	0	1	3.3
Education level										
Secondary/highschool diploma	2	20	0	0	0	0	0	0	2	6.7
Vocational/technical diploma	1	10	0	0	0	0	0	0	1	3.3
Bachelor's degree	2	20	4	44.4	1	12.5	2	66.7	9	30
Master's degree	3	30	4	44.4	4	50	1	33.3	12	40
Doctoral degree	2	20	1	11.1	3	37.5	0	0	6	20
Employment status										
Employed	4	40	8	88.9	6	75	2	66.7	20	66.7
Employed and studying	0	0	0	0	1	12.5	1	33.3	2	6.7
Student	1	10	0	0	0	0	0	0	1	3.3
Unemployed	2	20	0	0	0	0	0	0	2	6.7
Retired	1	10	0	0	1	12.5	0	0	2	6.7
Other[a]	2	20	1	11.1	0	0	0	0	3	10
Country of residence										
Argentina	0	0	0	0	1	12.5	0	0	1	3.3
Australia	0	0	0	0	0	0	1	33.3	1	3.3
Belgium	0	0	0	0	1	12.5	0	0	1	3.3
Denmark	0	0	0	0	1	12.5	0	0	1	3.3
Germany	2	20	0	0	0	0	0	0	2	6.7
Portugal	2	20	1	11.1	2	25	2	66.7	7	23.3
Spain	0	0	0	0	1	12.5	0	0	1	3.3
Sweden	0	0	1	11.1	0	0	0	0	1	3.3
Switzerland	1	10	0	0	0	0	0	0	1	3.3
Türkiye	1	10	0	0	0	0	0	0	1	3.3
United Kingdom	1	10	3	33.3	1	12.5	0	0	5	16.7
United States	3	30	4	44.4	1	12.5	0	0	8	26.7

Note. $N = 30$ ($n = 10$ for DCP; $n = 9$ for Parents of DCP; $n = 8$ for Healthcare professionals; $n = 3$ for Donors) Percentages are calculated within each stakeholder group. Estimated age was calculated as 2026 minus the participant's reported year of birth. DCP = donor-conceived people.

[a] Other includes freelance, self-employed, and part-time employment.

Data Analysis

All focus-group sessions were audio-recorded with participants' consent and subsequently transcribed verbatim. Participant-identifiable information was removed from transcripts before analysis. Transcripts were imported into NVivo 15 to support data management and coding.

Focus-group data were analysed using an approach informed by the Framework Method (Gale et al., 2013). The analysis involved familiarisation, coding, development and refinement of an analytical framework, and interpretation of coded data. A combined deductive-inductive approach was adopted, whereby the preliminary Care Pathway and study objectives informed the analysis while allowing additional concepts and support needs to emerge from participants' accounts.

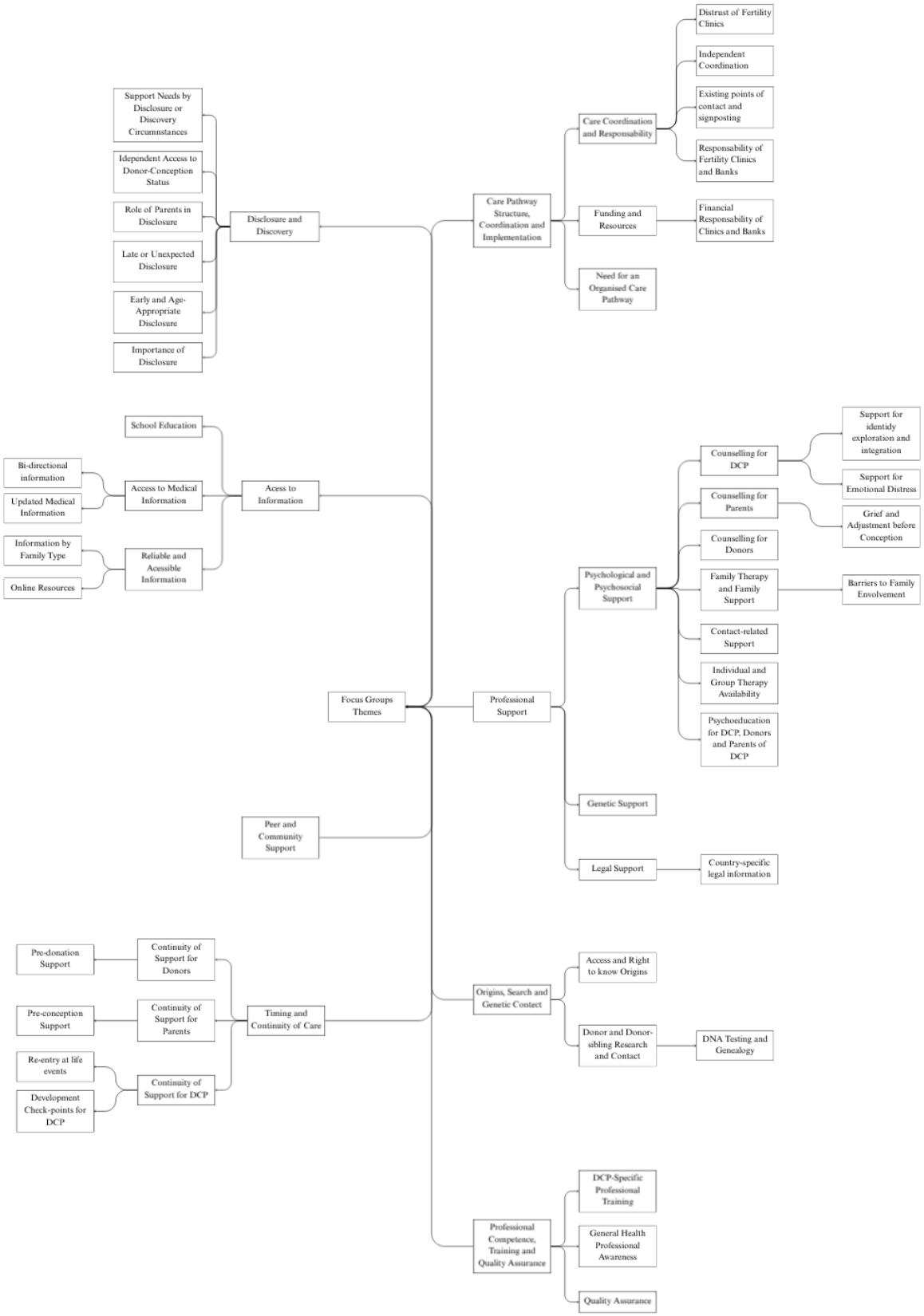
The coding framework was refined and organised hierarchically into broader categories and more specific codes. For each code, coded extracts were reviewed to support interpretation and the selection of illustrative quotations. Coding-reference counts were used to facilitate navigation of the dataset but were not interpreted as measures of thematic prevalence or importance. The complete coding framework, including code descriptions, reference counts and illustrative examples, is provided in Appendix B.

RESULTS

The qualitative analysis identified several interrelated topics concerning support needs and the organisation and delivery of care in donor conception. Figure 2 provides a visual overview of the coding structure developed through the analysis, while the complete coding framework, including code descriptions and illustrative examples, is provided in Appendix B. The main topics that emerged from the focus group discussions are described below and illustrated with representative participant quotations.

Figure 2

Categories, Subcategories, and Codes Identified Through the Qualitative Analysis



Care Pathway Structure, Coordination and Implementation

Participants highlighted the need for a clear care pathway, particularly when questions or support needs arise and individuals may be uncertain about what to do or where to turn:

> It would feel kind of comforting for me to see that there's a system worked out that I can just, like, follow steps or something. So, maybe, like, a flowchart or something, um, that I can follow whenever I'm ready to... (Donor Conceived Person, Focus Group 1)

Fertility clinics were a particularly debated point of contact. Although they represented an intuitive starting point, participants expressed considerable distrust of clinics, particularly regarding their independence and commercial interests, and questioned the appropriateness of returning to a fertility setting for support later in life: "[Counselling] should be, like, always independent from the clinics, because [...] we kind of know now that they can't be trusted, so when there's a commercialization, then it should always be independent from that" (Donor Conceived Person, Focus Group 1).

Despite these concerns, participants did not consider fertility clinics and banks exempt from responsibility because of their centralised role in donor conception. Rather than positioning fertility clinics as long-term coordinators of the pathway, participants tended to envision them as a bridge to independent support, including through contributing to its funding: "[I] wouldn't trust them [fertility clinics and banks] either to do this, but what I would trust them to do is to write a check" (Donor Conceived Person, Focus Group 3). Independent or centralised coordination was favoured, with fertility clinics potentially sharing responsibility for sustaining the resources required to make the pathway available over time.

Disclosure and Discovery

Participants emphasised the importance of disclosure, with early and age-appropriate disclosure generally favoured over withholding donor-conception status. Growing up with this knowledge was described as facilitating its integration into the individual's developing understanding of themselves. One participant reflected, "I was very fortunate. My mom was very honest from the get-go about how we were conceived, so I felt like that really helped me in my development" (Donor Conceived Person, Focus Group 5).

The possibility of later discovery was considered increasingly difficult to prevent, particularly given the accessibility of genetic testing: “So, very naive in thinking that your kid's not gonna find out. We have a saying in my community, it's not if, it's when. And how do you want your kid to find out?” (Donor Conceived Person, Focus Group 2)

However, relying solely on parents to disclose donor-conception was not considered sufficient, and participants suggested that DCP should eventually have a mechanism to access this information independently: “I think the problem is when the responsibility lies on the recipient parent, it's not foolproof” (Parent of Donor Conceived Person & Healthcare Professional, Focus Group 4).

Late or unexpected discovery was distinguished from growing up with knowledge of donor conception. Participants described accidental or delayed discovery as potentially life-altering, particularly when it disrupted family relationships and personal identity. One participant, who discovered their donor-conceived status unexpectedly in adulthood, recalled that “it wasn't as much of a surprise as it could have been, but it was life-altering” (Donor Conceived Person, Focus Group 4).

These different disclosure circumstances were considered relevant to subsequent support needs. Rather than assuming a uniform response to donor conception, participants suggested that the pathway should accommodate differences between those who had integrated this information from an early age and those who discovered it later or unexpectedly.

Access to Information

Participants highlighted the need for reliable and easily accessible information on donor conception. Online resources were considered particularly important, as the internet was often described as the first place people would turn to, although identifying trustworthy sources could be difficult. One participant suggested that information should be provided through an independent, verified source: “[A] government agency that is not biased, […] a place that you can go to and have some assurance that at least what they have up on their website have been verified” (Donor Conceived Person, Focus Group 2).

Information needs were also described as varying according to individual and family circumstances. Participants suggested that “[t]he resources will be different depending, potentially, on family type [...] splitting it down by family type” (Parent of Donor Conceived

Person & Healthcare Professional, Focus Group 4), suggesting that resources should reflect different family structures and developmental stages rather than providing uniform information.

Access to medical information represented a distinct concern. Participants emphasised not only access to donors' medical histories, but the need for this information to remain current over time. One participant described regular updates to donor health information as something that "needs to be mandated internationally" (Parent of Donor Conceived Person, Focus Group 2), alongside secure systems for maintaining these records. Donors also expressed an interest in receiving relevant health updates concerning people conceived through their donations: "But as a donor, I haven't heard any ... about, about the other side. [...] We, we would like to know if... if the… the child is, or...or the, the, the person, is well or not [...]" (Donor, Focus Group 3).

Finally, participants identified schools as an important setting for increasing awareness of donor conception and promoting the inclusion of different family structures. This was considered particularly relevant to preventing DCP from feeling different or perceiving their family as somehow less legitimate:

> What happens when my child goes to school? What if they feel different? Or what if they're made fun of, or they're made to feel [...] that something's wrong with our family. [...] There is the responsibility of teachers to help me, to help the child, and the rest of the people in their class understand about different family setups. (Parent of Donor Conceived Person, Focus Group 6)

Professional Support

Professional support emerged as an important component of the proposed pathway, although participants did not describe it as something that would be necessary for every donor-conceived person or at every stage of life. Rather, discussions pointed towards support being available when particular questions, experiences or difficulties arose, and adaptable to individual circumstances and preferences. Psychological and psychosocial support received particular attention, with participants identifying distinct needs among DCP, parents and donors.

For donor-conceived people, participants described counselling as a potentially important form of support for understanding and integrating donor conception into their identity, which could continue to evolve over time even among those who had known about

their conception from an early age, “I think that identity-focused support is something that's always needed. I think, you know, I grew up knowing, that was fine” (Donor Conceived Person, Focus Group 5).

Participants also described circumstances in which donor conception could be associated with considerable emotional distress. For example, the ongoing nature of this uncertainty about not knowing how many genetic siblings might exist was described as potentially distressing:

> Living with that unfinished loop [...] of never knowing how many siblings you might have, that can have catastrophic effect. That takes quite a while to come to terms with […] these are real things that donors have to live with as well. (Donor Conceived Person, Focus Group 4)

The discussions also extended beyond support for donor-conceived people themselves, with participants describing counselling for parents of DCP as relevant across different stages of parenting through donor conception. This included navigating disclosure and conversations with the child, anticipating needs that might emerge as the child grew, and supporting parents in responding to the longer-term implications of donor conception. As one participant described, choosing donor conception was “a lifelong decision” (Healthcare Professional, Focus Group 6) with consequences that could require different responses at different stages.

Some of these needs began before conception. Participants discussed the importance of addressing parents’ expectations, decision-making and, where relevant, grief associated with not conceiving using their own gametes. One parent recalled, “I was not screened. I was not, you know [...] have you gone through therapy to deal with your grief? [...] none of that was done” (Parent of Donor Conceived Person, Focus Group 6). Another described counselling before treatment as particularly valuable: “It was all about the implications of using a donor, how I might have those conversations with the child, how I feel about it [...] which for me was so helpful” (Parent of Donor Conceived Person, Focus Group 6).

Others described entering treatment without comparable opportunities to reflect on these issues and outlined the support they believed should be in place:

> Here is what your child is going to need. We need to disclose early. You need to be talking about this from an early age. Here are some ways to do it. Later on, your child

> is going to need maybe genetic counseling [...] so that we know, like, what to expect. (Parent of Donor Conceived Person, Focus Group 6)

Similar concerns were raised in relation to donors. Participants argued that counselling should extend beyond assessing suitability to donate and provide an opportunity to consider the broader and longer-term implications of donation. Donors were described as a group whose support needs could easily be overlooked, including at the point of donor recruitment: "And also, quite frankly, even these donors have to be counseled. If they don't think somebody's gonna come knocking on their door in 10 years, they're really…you know, really naive about it [...] and you have to be prepared" (Donor Conceived Person, Focus Group 2).

Questions surrounding contact between DCP, donors and donor-related individuals introduced further emotional complexities. Participants described a need for emotional preparation around contact, including anticipating different possible outcomes and managing the responses that could follow. One DCP described the connection with their donor as initially being "like a fireworks" (Donor Conceived Person, Focus Group 1), explaining that people "need to be prepared" for both intense connection and possible rejection. Preparation was therefore discussed not only in relation to contact itself, but also to anticipating different possible outcomes and managing the emotional responses that could follow:

> I know there's gonna come a day when we meet someone who's a sibling who's only just found out [...] And I need to prepare her for that. [...] She's gonna meet people who are traumatized by this knowledge more than she is. (Parent of Donor Conceived Person, Focus Group 2)

Professional support was also discussed in relation to the family as a whole. However, participants cautioned against assuming that relatives would necessarily be willing to participate, particularly following disclosure later in life: "When you work with older or late disclosure [...] not every parent from that generation still wants to [...] be part of the family therapy" (Healthcare Professional, Focus Group 6).

Fear of judgement or blame could further complicate family involvement, with participants describing how parents might enter psychological support expecting their previous decisions to be criticised.

At the same time, participants were clear that professional psychological support should not assume a single format. Individual preferences differed substantially, particularly regarding

individual and group-based support. While some valued the opportunity to connect with others with similar experiences, others might find a group setting uncomfortable:

> Because we're all such different people, some people would absolutely not want to discuss this in a group, but others might really value meeting other people who have got similar questions [...] it could be left to each individual to decide what path would work best for them. (Parent of Donor Conceived Person & Healthcare Professional, Focus Group 4)

Alongside counselling and therapy, participants discussed the value of psychoeducation across the different people involved in donor conception. As one participant reflected, “For all members of the triad, I think it's super important to have very good preparation, and donors, obviously, as well” (Parent of Donor Conceived Person, Focus Group 2).

Professional support was not limited to psychological care. Legal guidance was considered particularly relevant because participants described substantial differences between countries in relation to donor anonymity, access to identifying information and the age at which such information could be obtained. One participant illustrated how access could even differ between people within the same jurisdiction according to when they were conceived:

> We have 3 tiers of donor-conceived people at the moment, so people born before 1991 have no access to anything. People born between 1991 and 2005 [...] are only allowed limited information and anyone born after 2005 is allowed to find out details about their donor after they turn 18. (Donor Conceived Person, Focus Group 4)

Genetic counselling was also considered potentially useful, particularly when medical questions emerged and complete genetic information was unavailable. However, participants did not support its routine introduction simply because someone was donor-conceived. One participant specifically cautioned against introducing genetic counselling too early in a way that might unnecessarily associate donor conception with disease or genetic danger, suggesting instead that it should become available when relevant needs emerged:

> And maybe you shouldn't create the idea of danger of genetic counseling and disease at a very young age, because you are creating more issues [...] So, why bring genetic

> counseling to donor conceived person with 16, 17, maybe later, when they need… Yeah. waiting a little bit. (Healthcare Professional, Focus Group 3)

Timing and Continuity of Care

Participants did not conceptualise care as a linear sequence of interventions delivered at predetermined times. Instead, support needs were described as changing across the life course, requiring a pathway that remained accessible over time and allowed individuals to enter, leave and re-enter care according to their circumstances. One participant explained this process as "absolutely lifelong, and it's not linear. You jump back, jump forward, depending on where you are in your life" (Donor Conceived Person, Focus Group 4).

For DCP, participants suggested that developmental stages could provide opportunities for proactive check-ins. These were not described as mandatory interventions, but as points at which information, understanding and possible support needs could be revisited. Participants noted that children's capacity to understand donor conception changes with age and that different questions may emerge over time: "At every age, they develop differently, they have different questions, their understanding changes" (Parent of Donor Conceived Person, Focus Group 2).

Rather than establishing a fixed schedule, participants therefore suggested opportunities to check in at relevant developmental stages: "maybe at age 12 or 13, this should happen [...] maybe there needs to be identifiable timelines in a donor-conceived life" (Donor Conceived Person, Focus Group 2).

However, developmental age alone was not considered sufficient. Participants described particular life events as potentially creating new support needs, even where donor conception had previously caused little difficulty. This applied across those involved in donor conception. For example, one donor described how considering having children of their own raised new questions:

> Right now, I am in a different point of my life, and I'm considering having children of my own, and I'm also thinking, okay, so when I have children, what I'm gonna talk to them about this, because there will be potential siblings out there. (Donor, Focus Group 4)

Continuity was also considered important for parents. Although participants strongly supported support before conception, they cautioned that prospective parents might not yet be able to anticipate or integrate all of the issues that could later become relevant. One participant described this tension: “The preconception counseling seems so imperative, but we're almost catching them too early, and they're not able to really integrate everything that they need” (Healthcare Professional, Focus Group 3).

Pre-conception support was nevertheless viewed as an important starting point, particularly for addressing the emotional and practical implications of using donor conception before treatment.

A similar principle was applied to donors. Participants considered pre-donation support an important entry point into care, while emphasising that opportunities to re-enter support should remain available as the longer-term implications of donation emerged: “He was regretting his choice, and the fertility clinic had told him that 7 children had been created, and he wanted to know that those 7 children were safe [...] and he spiraled [...] Donors deserve support as well” (Donor Conceived Person, Focus Group 4).

Peer and Community Support

Participants highlighted the importance of connecting with others with shared lived experiences, particularly as a source of validation, understanding and reduced isolation. As one participant described:

> I think the DCP support. The peer, peer-to-peer is really crucial. I think just seeking out other people and saying, oh my god, what the hell happened to you, and what happened to me, and do you feel this way, is really crucial. (Healthcare Professional, Focus Group 3)

The value of peer support was described across different circumstances and stages of life. For younger DCP, opportunities to interact with others with similar experiences were considered potentially helpful without necessarily requiring formal psychological intervention. For adults, particularly following late discovery, peer support was associated with recognition and the feeling of “not being the only one isolated” (Healthcare Professional, Focus Group 6).

Participants also described community organisations and support groups as spaces where experiences could be shared and guidance obtained. This included opportunities to exchange experiences related to donor conception and contact with genetic relatives: “You find your peers, you find people. Same as you. Different story, but at the end, we all are the same. With this donor-conceived thing. And it's really nice to share, actually, and to exchange” (Donor Conceived Person, Focus Group 1).

Community support could also provide forms of connection and validation that participants considered difficult to obtain through information or professional resources alone. One Parent described lived experience, peer groups and online discussion as “sometimes even more [...] helpful and validating” (Parent of Donor Conceived Person, Focus Group 5), while another described community as “the most impactful” source of support in their own experience (Donor Conceived Person, Focus Group 5).

Finally, peer organisations were considered a potential source of practical guidance within the pathway. Existing organisations were described as possible hubs through which people could obtain advice and connect with relevant support: “Peer-to-peer organization, non-profit. I think that would be a good hub where people could go to get the advice” (Donor Conceived Person, Focus Group 6).

Origins, Search and Genetic Contact

Participants described access to genetic origins as an important consideration for DCP, with some framing knowledge of one’s origins as a fundamental right and as relevant to identity development. For some, origins extended beyond identifying genetic relatives to understanding aspects of ethnic and cultural background, particularly where the donor had a different ethnicity, suggesting that “In the building [of] yourself, you need to know where you come from, and that's a basic right, actually” (Donor Conceived Person, Focus Group 1).

The meaning of origins was not limited to identifying the donor. Participants also raised access to donor siblings and broader aspects of genetic and ethnic identity. One participant argued that DCP should have the opportunity to know close genetic relatives: “I think everyone has a right to know every single person that they're related to in a [...] substantial percentage, like a half-sibling” (Parent of Donor Conceived Person, Focus Group 5).

Participants also described searching for and establishing contact with donors and donor siblings as highly variable experiences. Interest in contact differed between individuals, as did

the relationships that developed following contact. Some maintained contact and met genetic relatives, while others experienced limited interest or relationships that subsequently ended: “Finding out about that, getting to meet with [...] the siblings [...] has been [...] a very big help in understanding things [...]” (Donor Conceived Person, Focus Group 2).

Commercial DNA testing had substantially changed how these searches could occur. Participants described services such as MyHeritage, 23andMe and Ancestry as important routes for identifying donors and donor siblings, sometimes providing information that would otherwise have remained inaccessible. One participant reflected that “Thanks to [MyHeritage] [...] if not, we would never have found some of our siblings or genitors” (Donor Conceived Person, Focus Group 3).

However, DNA testing could also result in significant information being received unexpectedly and outside any supportive context. Participants described discovering genetic relatives or aspects of their biological history through routine notifications from commercial platforms:

> With DNA testing, it all kinds of comes out of a sudden [...] you're just checking your phone, and then you have a message from this DNA testing website [...] and you're kind of bombarded with [...] the most important information of your biological history [...] So, I guess it would be nice to have the autonomy to choose when to have what kind of information. (Donor Conceived Person, Focus Group 1)

Professional Competence, Training and Quality Assurance

Participants emphasised that access to professional support alone was insufficient if those providing care lacked specific knowledge of donor conception. General experience in counselling or related areas was not necessarily considered equivalent to understanding the experiences and needs of DCP: “All of our [...] social workers, all of our assistants always end up being people who are trained in adoption trauma. But they're not really trained in this, and while there's a lot of overlap […]” (Donor Conceived Person, Focus Group 2).

Importantly, participants also distinguished donor-conception-specific expertise from fertility counselling. Fertility professionals were viewed as primarily oriented towards the reproductive process, whereas longer-term support required professionals who understood the lived experience of being donor-conceived: “[...] if you put a donor-conceived person in front

of a fertility counsellor, that's not going to go very, very well [...] [we need] counsellors who do actually understand [...] what it means to be donor-conceived" (Donor Conceived Person, Focus Group 4).

Participants therefore called for donor-conception-specific training for professionals involved in providing support. This was particularly emphasised for counsellors and therapists, with specialised training viewed as necessary to ensure that professionals understood the specific experiences associated with donor conception:

> I think it would be really, really good if there were also [...] good training workshops and courses for practitioners to give them the training they need to do it right, because there's a massive dearth in the skill set to support people. (Parent of Donor Conceived Person, Focus Group 2)

However, the need for greater awareness extended beyond specialist psychological care. Participants described encounters with general healthcare professionals who lacked knowledge of donor conception or provided advice that was inconsistent with current evidence. One participant recalled, "[t]he advice that I was given time and time again was incorrect information. So my OB-GYN was counseling me to disclose as my children were adults. My pediatrician was visibly uncomfortable when I told her I used a donor" (Parent of Donor Conceived Person, Focus Group 6).

Participants consequently discussed a broader need to increase awareness among professionals likely to encounter DCP and their families, including doctors, pediatricians and fertility-clinic staff. This included understanding donor conception beyond its role as a fertility treatment and recognising the longer-term implications for donor-conceived people.

> There is [...] the rights of the children within the fertility clinic. How can we be more aware of the rights of the children, how to integrate them within the care that we offer at the fertility clinic? Because I think that's still missing [...] [the clinic] just still sees donor conception as a treatment. (Healthcare Professional, Focus Group 6)

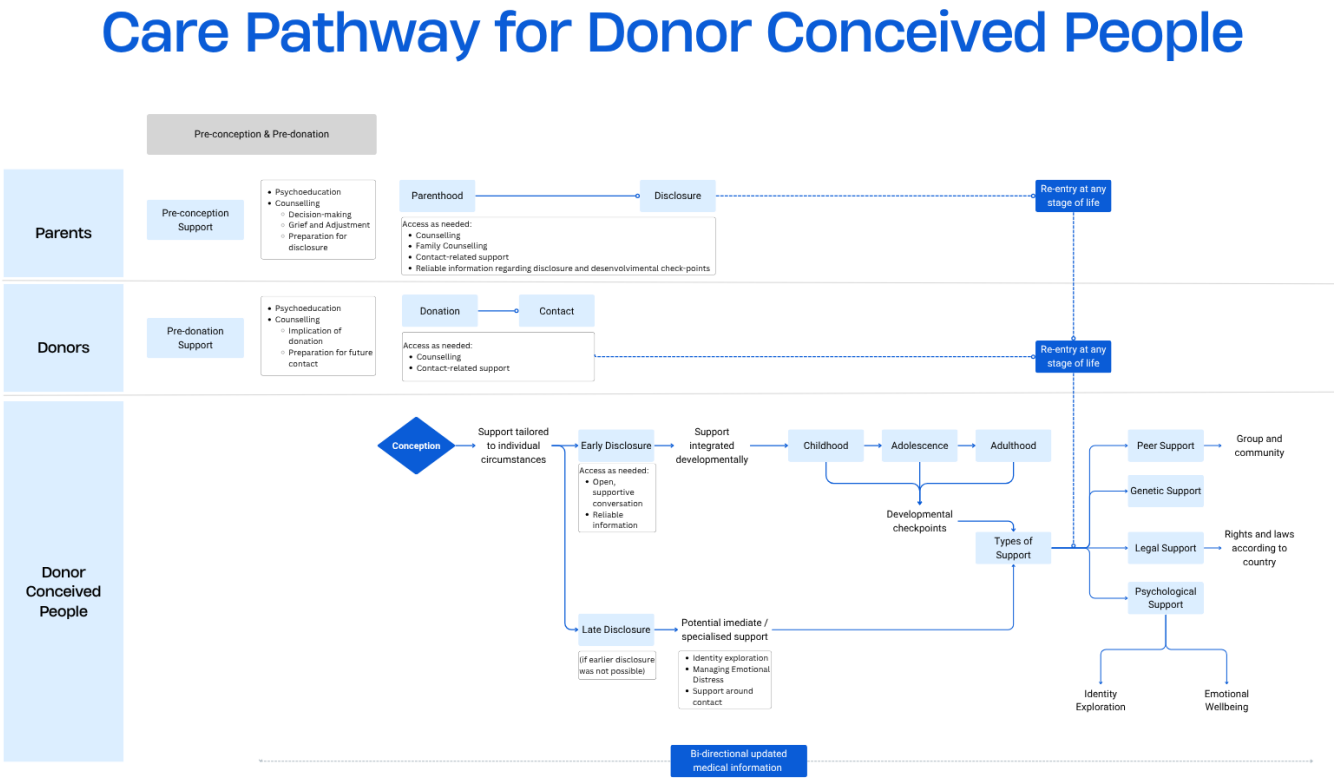
Finally, participants raised concerns about variation in the quality and expertise of available professionals. Accreditation, certification or other forms of quality assurance were suggested as ways of identifying practitioners with appropriate donor-conception-specific competence: "I wish there was, like, some sort of certification, like, this therapist has been DCP

certified [...] they know the best practices, the [...] evidence-based research [...] and [...] this person I can go to" (Donor Conceived Person, Focus Group 6).

The preliminary Care Pathway was refined in light of participants' reflections and suggestions during the focus groups. Figure 3 presents the resulting co-constructed pathway for informational and psychosocial support in donor conception.

Figure 3

Co-constructed Care Pathway for Informational and Psychosocial Support in Donor Conception



DISCUSSION

The focus groups contributed to the development of a co-constructed Care Pathway for informational and psychosocial support in donor conception (Figure 3). Participants emphasised access to psychological support, reliable information and professionals with knowledge of donor conception. They also identified a role for legal and genetic guidance, peer support and community organisations. The resulting pathway incorporates preparation before conception or donation, support during childhood and adulthood, and opportunities to re-enter care when circumstances change. Independent coordination, professional training and funding were discussed as essential conditions for the Care Pathway.

Although the preliminary Care Pathway was primarily centred on support for donor-conceived people, the focus-group discussions highlighted that their informational and psychosocial needs cannot always be considered in isolation. Participants identified support needs among parents and donors that may shape how donor-conceived people understand and navigate their conception circumstances. This represented an important development from the preliminary pathway, as the co-constructed pathway expanded beyond its initial focus to incorporate support for parents and donors at relevant stages of the donor-conception process.

Previous research has highlighted that donor conception remains "too often framed as a (short-term) treatment for infertility and involuntary childlessness rather than a family-building practice with enduring psychosocial consequences" (Goedeke et al., 2026, p. 15), and the pre-donor-conception counselling requirements are variable across different countries, while professional and institutionally required post-donor-conception psychosocial support remains very limited. Participants of the focus groups described needs extending beyond these circumstances, including identity-related questions and access to updated medical information.

Professional support was a prominent component of the proposed Care Pathway, particularly psychological and psychosocial support. Participants did not suggest that counselling should be routinely required for all those involved in donor conception, but rather that appropriate support should be accessible when individual needs arise.

For DCP, identity was one context in which psychological support was considered relevant. This is consistent with earlier research describing donor conception as potentially relevant to the construction and understanding of identity (Turner & Coyle, 2000), adding that they might experience emotional or challenging emotional responses associated with donor-conception-related experiences.

The focus-group discussions further suggested that the circumstances in which DCP learn about their conception may shape the type of support required. Differences in emotional responses have been reported according to age at disclosure, with negative reactions being significantly more frequent among those who learned about their donor conception later than among those informed before adolescence (Lampic et al., 2022). Reflecting the stakeholders' perspectives, the proposed Care Pathway therefore distinguishes between support needs according to the circumstances of disclosure, with informational support emphasised in the context of early disclosure and counselling considered particularly relevant following later disclosure.

The discussions also identified support needs among parents and donors. For prospective parents, these included support with decision-making and, where relevant, grief associated with not conceiving using their own gametes. These areas are also recognised within professional guidance on donor conception, which identifies decision-making, grief and loss, disclosure and the longer-term impact on the family as relevant areas for psychoeducational counselling (American Society for Reproductive Medicine, 2024). Once parenthood was established, participants described needs related to conversations about donor conception and circumstances that could emerge as children grew. The importance of preparing parents for disclosure is also supported by evidence showing that disclosure decisions and practices are influenced by multiple context-related factors (Duff & Goedeke, 2024).

Support needs were similarly identified among donors. Participants emphasised preparation for the longer-term implications of donation, including discussing donation within their own families and considering the possibility of future contact with DCP. Concerns regarding future relationships are also evident among donors themselves, including uncertainty about relationships with donor-conceived offspring and the implications of non-anonymous donation (Pinto da Silva et al., 2022).

The possibility of returning to support was relevant across stakeholder groups. Participants discussed questions arising when becoming a parent, identifying donor siblings, receiving new health information or being approached for contact. Donor conception has been described as having enduring psychosocial implications, with a corresponding need for appropriate support across different stages and circumstances (Goedeke et al., 2026). Within the proposed Care Pathway, re-entry provides an opportunity to respond to needs emerging after previous involvement with services has ended. This requires information about where appropriate support can be accessed when new questions or circumstances arise.

Information was another important component of the proposed pathway. Participants emphasised not only access to information about available services, genetic and medical information, but also the importance of this information being reliable, accessible and, where possible, available through trustworthy online resources. Participants also emphasised access to updated medical information, including the possibility that relevant health information may emerge after donation. The importance of medical information is also evident in research on donor-conceived people's information-seeking, where it has been identified as a motivation for seeking information about or contact with donors (Jadva et al., 2010; Macmillan et al., 2021).

Participants distinguished between specialist knowledge required by professionals providing donor-conception-related support and broader awareness among healthcare professionals who may encounter DCP, parents or donors and need to recognise relevant concerns or provide appropriate signposting. Previous research has similarly indicated that DCP value knowing where specialist counselling can be accessed when needed (A. Schrijvers et al., 2019). Professional training and quality assurance should therefore accompany the development of referral pathways, rather than assuming that the availability of psychological or other professional services alone ensures appropriate donor-conception-related care.

Peer support and community organisations were valued for shared experience, recognition and practical knowledge. The value of peer contact has also been identified directly among DCP, who described opportunities to exchange experiences with other donor-conceived people as an important form of support (A. Schrijvers et al., 2019). Peer and community support may therefore provide a form of support that is distinct from professional intervention, particularly through access to shared lived experience.

Coordination was discussed in relation to the independence and trustworthiness of services. Although fertility clinics and gamete banks were identified as potential sources of information and referral, participants questioned their suitability as long-term coordinators. Goedeke et al. (2026) argue that the state and ART providers should share responsibility for professional psychosocial provision. Participants' preference for independent coordination adds a specific proposal about how that responsibility might be organised. An independent structure could retain referral links with fertility services, although its governance, responsibilities and feasibility would require further consideration. Funding was closely related to these organisational concerns. Participants suggested that institutions involved in donor conception could contribute financially to support provision.

The developmental checkpoints proposed in the focus groups offer a possible way to organise opportunities for follow-up during childhood and adolescence. These could provide

occasions to explore current understanding, questions and preferences. The discussions did not establish which topics should be introduced at particular ages.

Studies of disclosure provide relevant evidence for this work. Seven-year-old children showed limited understanding of donor conception despite disclosure having begun before age four (Blake et al., 2010). More positive family relationships were reported among adolescents whose parents had begun disclosure before age seven than among those told later, although emotional and behavioural difficulties did not differ between these groups (Ilioi et al., 2017). Follow-up into early adulthood also identified an association between disclosure before seven and less negative relationships with mothers (Golombok et al., 2023).

Parental guidance could draw on resources developed specifically to assist conversations about donor conception. Concerns about children's capacity to understand and difficulties discussing donor conception have been identified among the factors influencing disclosure decisions (Duff & Goedeke, 2024). A tool was developed to assist parents with these conversations through an individual telling plan and content organised for children aged 1 to 7, 8 to 12 and 13 to 16 years. These categories were informed by developmental theory and feedback during the tool's development (Hershberger et al., 2023). They provide a structure for the resource rather than validated ages for introducing specific information.

Strengths, limitations and future research

The inclusion of DCP, parents, donors and healthcare professionals brought lived experience and professional perspectives into the refinement of a concrete Care Pathway. International participation also exposed the pathway to different legal and organisational contexts. These features strengthen its relevance to service development, while the opportunity to question a preliminary version helped identify both support needs and conditions affecting delivery.

Recruitment through organisations, social media and professional networks may have attracted people with a particular interest in donor conception or experience of seeking support. The groups cannot establish how common the identified needs are in the wider population. Stakeholder representation was uneven, with limited donor participation, and eligibility required English proficiency. Online participation enabled geographical reach but also required access to suitable technology and a setting in which participants could discuss personal experiences.

The mixed composition of the groups may have encouraged exchange while influencing which views participants felt comfortable expressing. Presenting an existing pathway provided focus but may have directed attention towards its initial components. The combined deductive and inductive analysis allowed additional issues to be considered, although interpretation remained shaped by the study aims and analytical decisions. As all participants were adults, proposals concerning childhood and adolescence reflect adult perspectives rather than direct consultation with young DCP.

Further research should examine the pathway's clarity, relevance and acceptability among intended users, including those with little previous involvement in donor-conception organisations.

In sum, the present study and its co-constructed pathway provide a framework for connecting support needs with resources across the lives of DCP, parents and donors. Its contribution is to make the organisation of support explicit, including access beyond fertility treatment and renewed contact when circumstances change. Whether it improves access and experiences will depend on how these functions are implemented and evaluated within services.

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Appendix A
Focus Group Session Guide

Duration: Approximately 60 minutes
Format: Online
Target participants: Donor-conceived people (DCP), parents of DCP, donors, and healthcare professionals

1. Welcome and Introduction (10 minutes)

Participants and facilitators are introduced. The study and the purpose of the focus group are briefly presented.

2. Initial Reflection Activity (15 minutes)

Participants are invited to reflect on the following questions:

1. What do you think are the three main things that need to be in place to support emotional wellbeing around being donor conceived?
2. What are three things you would change in donor conception practices to protect the well-being and rights of donor-conceived people?
3. What is one thing you believe is universally true about the donor-conceived experience that others might not realize?

3. Presentation and Discussion of the Preliminary Care Pathway (30 minutes)

The preliminary Care Pathway is presented and explained. Discussion is guided by the following questions:

1. What was your first impression when looking at the Care Pathway? What stood out to you immediately?
2. Looking at the types of support described, did you have any idea where you could access that kind of support? Where would you look for it? Is there any type of support that you feel is missing?

3. The model shows "Point of Disclosure" as the starting point. In your experience, what came first - the need for information or the need for emotional support? Which do you think should come first in a pathway?
4. Which type of support do you think is most time-sensitive? If someone does not receive it at the right moment, is the opportunity lost?
5. The model suggests a linear progression, but for many people needs appear in waves or shift over time. Does this resonate with your experience? How could a pathway reflect that someone may not be "ready" for a particular type of support at a given moment?
6. Who do you think is the best person to help someone navigate this pathway? A family doctor? A genetic counsellor? A therapist specialised in donor conception? A peer supporter or community organisation? Someone else?
7. If a DCP were to receive support within this pathway, what format would work best? Online or in-person? Group-based, individual, or a mix? Synchronous (live) or asynchronous (materials you explore on your own)? Why?
8. How could some of these supports be materialised in a practical, accessible way? For example: Legal support - a clear leaflet summarising the current legal framework in your country; healthcare navigation - a checklist for what to ask or expect; rights and responsibilities - simple guidance notes instead of technical documents. What formats or resources would be most useful?

4. Closing (5 minutes)

The session is summarised, participants are thanked for their contribution, and information is provided about access to the study results.

Appendix B
Coding Framework

Parent Code	Child code	Child code2	Child code3	Description	References	Example
Care Pathway Structure, Coordination and Implementation				How the pathway should be structured, coordinated, funded and implemented	48	“it would feel kind of comforting for me to see that there's a system worked out that I can just, like, follow steps or something. So, maybe, like, a flowchart or something, um, that I can follow whenever I'm ready to, like have more information?”
	Need for an organised Care Pathway			Perceived need, value, or usefulness of an organised Care Pathway, including concerns about the absence, fragmentation, or inadequacy of existing support systems.	9	“I didn't know, I was so confused, I didn't know what the next steps would be."
	Care coordination and Responsibility			Existing professionals, services, or organisations that may act as points of contact and direct individuals towards appropriate donor-conception-related information or support.	25	“If there could be some sort of, like, government… place to go for general information, and for, like, where you can look up and say, where are there psychologists that are trained in donor conceived?”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
		Existing points of contact and signposting		Professionals or services already encountered across the life course (ex: doctors, teachers, organizations) that could identify needs, provide information, or signpost to appropriate support.	5	“We now have Donor Conceived UK, the peer-to-peer organization, non-profit. I think that would be a good hub where people could go to get the advice, and then be signposted out to the professionals, for example, so, you know, your professional counselling support. I think… Clinics could be a signpost.”
		Responsibility of Fertility Clinics and Banks		Responsibilities attributed to fertility clinics and gamete banks in providing information, support, follow-up, or other forms of care to DCP and families.	4	“And my first thought, when you asked the question, was that it should be the responsibility of whoever kind of did a match, even if it's not a match, like, if it… if you buy sperm from a cryobank, it's their responsibility to then support the person that's created from that.”
		Independent Coordination		Preference for donor-conception-related information, support, and referrals to be coordinated by an independent or neutral organisation.	4	“Yeah, like a government agency that is not biased, doesn't take money from, you know, cryobanks or anybody else, but it's a place that you can go to and have some assurance that at least what they have up on their website have been verified [...]”
		Distrust of Fertility Clinics		Distrust, concerns, conflicts of interest, or perceived limitations of fertility clinics in providing or coordinating support.	12	“They're all about sales, and not about… the people who come from it [...] I don't trust them to be good middle people.”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	Funding and Resources			Funding and other resources required to establish, provide, and sustain donor-conception-related information and support, including barriers arising from insufficient or inaccessible resources.	13	“But I think, you know, a huge, huge problem is funding. [...] It's hard to… do something like this without funds or resources.”
		Financial responsibility of Clinics and Banks		Fertility clinics or gamete banks contributing financially to support services or care systems.	9	“They should be all sending money based on what they earn. To somewhere that helps donor-conceived people. A centralised place, they will have to pay a separate tax, a separate whatever it is, because they're making tons of money,”
Disclosure and discovery				How, when and circumstances around becoming aware of donor conception, implications and different disclosure experiences.	41	“When you learn, it [...] could differ depending on that stage you are in your life [...] you process those things a little bit differently.”
	Importance of disclosure			Perceived importance of DCP being informed about their donor-conceived status.	2	“So, very naive in thinking that your kid's not gonna find out. We have a saying in my community, it's not if, it's when. And how do you want your kid to find out?”; "I was very fortunate. My mom was very honest from the get-go about how we were conceived, so I felt like that really helped me in my development."
	Early and Age-Appropriate Disclosure			Disclosure of donor conception from an early age, communicated in a developmentally appropriate manner.	9	"we talk about how you share this with your children when they're like, 2, 3, 4, 6, 7… it has to be different, because… just of their age. [...] they get told about this before they can even talk”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	Late or Unexpected Discovery			Discovery of donor-conceived status later in life or unexpectedly, including the implications associated with these circumstances.	6	“I found out by accident when I turned 54. Because my son was doing some DNA for a school project, and I said, hey, this could be fun, so I decided to do it too, and shocking...”
	Role of Parents in Disclosure			Parents' role, responsibility, decisions, or influence regarding disclosure of donor conception.	6	“I am in the process to, explain her, softly, that, yes, is, there are other ways that we can be a mother, with this, with this process. So, softly, I'm going to introduce some information.”
	Independent Access to Donor-Conception Status			Becoming informed of one’s donor-conceived status through formal or external mechanisms that do not depend exclusively on parental disclosure.	5	“(DCP should) get a letter that they are a donor-conceived person, independent from (their) parents with the information”
	Support Needs by Disclosure or Discovery Circumstances			Differences in support needs according to how and when a person learns about their donor-conceived status.	13	“I think in my mind, like, it would look different… of course, early versus late disclosure. I mean, again, I, like, compare… I mean, everyone's… you know… reactions and feelings about it are so unique.”
Access to Information				Information and educational resources needed to understand donor conception, origins, health and identity.	47	“I'm joining you on that, because I think that to find information, as it's really a new thing [...] it's really hard to connect, to know where to find the information.”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	Reliable and Accessible Information			Need for trustworthy, accurate, understandable, and easily accessible donor-conception information.	24	“So, it would be really nice to have, like, an easy access kind of… way that is, like, subtle and… I don't know… And especially maybe also that it's official, so that you know that these information are trustworthy”
		Online Resources		Websites, digital platforms, online content, or other internet-based resources that can be accessed independently for donor-conception-related information or guidance.	15	“I immediately went on the internet. Um, and it was kind of hard to find trustworthy information, especially there's, like, non, um… Um, I don't know, there's, like, none official information."
		Information by Family Type		Information and resources adapted to different family structures and their specific experiences and informational needs in donor conception.	3	“I like what P25 said about splitting it up into family types, because you'll want to look for the information that better reflects what you're going through, and not everything will be the same.”
	Access to Medical Information			Availability of and access to relevant medical, genetic, and health information concerning donors and donor-conceived people.	10	" so they don't understand necessarily what it means to have children when you're donor-conceived, and the implications of that, and the medical… the lack of medical information ramifications"
		Updated Medical Information		Need for donor medical information to remain accurate and updated over time.	3	"and updated medical history every year... and just kind of, different, different things like that that we're trying to fix in the industry."
		Bidirectional Health Information		Communication and updating of relevant health information in both directions between donors and DCP.	3	“But as a donor, I haven't heard any ... about, about the other side. [...] We, we would like to know if... if the… the child is, or...or the, the, the person, is well or not [...]”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	School Education			Education and awareness in schools about donor conception, assisted reproduction, and diverse family structures.	9	“And I believe that this starts actually at school, when we can actually normalize this kind of experience.”
Professional Support				Professional support provided by appropriately qualified professionals to address psychological, psychosocial, legal, genetic, and other specialised needs related to donor conception.	76	“There are situations where the child would need some form of emotional support, maybe through counseling and therapy, and that should be made available depending on each individual needs. If they need a family therapy, they should also be able to access this.”
	Psychological and psychosocial support			Emotional, psychological and family support needs of DCP, parents and donors.	66	“So, first information, then, that they have the opportunity to talk with a specialist, a psychologist, or a social professional [...] That they have the opportunity in all the process when they need to.”
		Counselling for DCP		Psychological or counselling support specifically informed by the experiences and needs of donor-conceived people.	13	“Well, I… Yes, based on… the donor-conceived people that have sought counseling, that I've spoken to. [...] their biggest frustration is, I am flooded with this trauma, confusion, all of these feelings, and I don't…And I need to talk to somebody who gets it. I need to talk, you know, I need help”
			Support for Identity Exploration and Integration	Support for understanding, exploring, or integrating donor conception and genetic origins into one's sense of identity.	3	“And I'm like, yeah, okay, cool for you, you're gonna be great parents. I don't judge or doubt that, but… It's not part of the identity. Love is not connected with identity. [...] but in the building yourself."

Parent Code	Child code	Child code2	Child code3	Description	References	Example
			Support for Emotional Distress	Psychological or emotional support for distress, psychological difficulties, or challenging emotional responses associated with donor-conception-related experiences.	3	“I am flooded with this trauma, confusion, all of these feelings [...] I need to talk to somebody who gets it. I need to talk, you know, I need help.”
		Counselling for Parents		Psychological, counselling, or emotional support for parents or prospective parents using donor conception.	19	“Yeah, I mean, looking at this, it's great, but it needs to start way before. Especially today. I mean, really, the parents need to be armed with… [...] I think that those parents need a lot more counseling.”
			Grief and Adjustment Before Conception	Support for prospective parents in processing grief, loss, and emotional adjustment before proceeding with donor conception.	4	“But, you know, it's really important we cover things like how to talk to your child, and when, and the importance of always known, and grief… grief counseling, and what it means to be creating a family this way.”
		Counselling for Donors		Psychological, counselling, or emotional support for donors before, during, or after donation and subsequent contact.	11	“And also, quite frankly, even these donors have to be counseled. If they don't think somebody's gonna come knocking on their door in 10 years, they're really…you know, really naive about it [...] and you have to be prepared.”
		Family Therapy and Family Support		Psychological or relational support involving family members to address communication, relationships, disclosure, or adjustment.	7	“There are situations where the child would need some form of emotional support, maybe through counseling and therapy, and that should be made available depending on each individual needs. If they need a family therapy, they should also be able to access this"

Parent Code	Child code	Child code2	Child code3	Description	References	Example
			Barriers to family Involvement	Difficulties, reluctance, unavailability, or other barriers to involving family members in psychological or family support.	5	“The other element with a family therapy, I think, it might be good. : But when you work with older or late disclosure, then donor conceive people are more older, living in their own family, having their own family, and not every parent from that generation still wants to you know, be part of the family therapy”
		Contact-related Support		Psychological and emotional support for DCP, parents and donors in preparing for and navigating donor- or donor-sibling-related contact.	4	“But I… I know there's gonna come a day when we meet someone who's a sibling who's only just found out, you know? And I need to prepare her for that. for being the one who has to share how they're related. And that's heavy for my kid, too.”
		Individual and Group Therapy Availability		Availability of both individual and group-based therapy options to accommodate different needs and preferences.	6	“it would be nice to have a mix of both scenarios [...] it would be nice to give everyone the room to talk about the specifics… the specific situation, but then later on, it might be nice to have a group to just get this feeling of, I'm not alone.”
		Psychoeducation for DCP, Donors and Parents of DCP		Psychoeducation aimed at helping DCP, parents, and donors understand donor conception, its psychosocial implications, and the range of experiences and considerations that may arise over time.	3	“I think education all around in all parties would be most beneficial. Saying, okay, if I'm donating, whether it's sperm or egg. What am I getting myself into? Not necessarily that, like, oh, I'm becoming a mother or father of X amount of kids, necessarily, but, like, you are a genetic ancestor.”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	Legal support			Legal information, guidance, or specialist advice related to donor conception, including rights, responsibilities, donor identity, and access to information.	6	“there may still be some crossover between [...] the legal advice, or legal information [...] An adolescent might want to get some information about from sources about what info they're entitled to [...] or maybe a genetic counselor if that child might have been told from birth, fully open environment”
		Country-specific legal information		Accessible information about donor-conception laws, rights, and procedures applicable within a specific country.	5	“legisl- legislation is really different over there as well. So sometimes it's complicated, because we don't have the same rights and depending where we are born.”
	Genetic support			Role, timing, relevance, or limitations of genetic counselling and needs.	2	"And maybe you shouldn't create the idea of danger of genetic counseling and disease at a very young age, because you are creating more issues [...] So, why bring genetic counseling to donor conceived person with 16, 17, maybe later, when they need… Yeah. waiting a little bit."
Peer and community support				Support, validation, shared experiences, and guidance provided through peers and donor-conception communities.	18	“I think the DCP support. The peer, peer-to-peer is really crucial. I think just seeking out other people and saying, oh my god, what the hell happened to you, and what happened to me, and do you feel this way, is really crucial.”
Origins, search and genetic contact				Needs related to identifying, locating, contacting or developing relationships with donors and donor-related siblings.	21	“we sometimes meet, like, not always all of them. [...] we are in contact, and we sometimes meet, yeah, but of course we also kind of experience setbacks with, like, people who are cutting off contact”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	Access and Right to know Origins			Access to information about genetic origins and donor identity, including the perceived right to obtain this information.	5	“When on MyHeritage, they received the news that there is someone new [...] trying to get firstly in contact with this person [...] ‘welcome to the big crew of half-siblings’ [...] it's really different [...] person-to-person.”
	Donor and Donor Sibling Search and Contact			Searching for, identifying, contacting, or establishing relationships with donors and donor-related siblings.	16	“we sometimes meet, like, not always all of them. Some are, like… Some have more interest than others, some of them are also, um… share more similarities than others, but we are in contact, and we sometimes meet, yeah, but of course we also kind of experience setbacks with, like, people who are cutting off contact,”
		DNA testing and genealogy		Use of DNA testing, commercial genetic databases, genealogy, or support in interpreting and navigating genetic matches.	6	“thanks to MyHeritage that is making billions of dollars on our back. Uh, they're existing, but thanks to that, if not, we would never have found some of our siblings or genitors.”
Timing and continuity of care				When support should begin, be revisited and remain available across the life course.	39	“I think it's very dynamic. [...] everyone processes different, so they need different things at different times. [...] I think it's not linear, and I think it's a lifelong journey.”
	Continuity of support for DCP			Continued availability of support for DCP over time rather than limiting support to a single event or stage.	22	“So I think the constant… as you're changing, as you get older, you know, your body changes, your mind's gonna change as well. I think having that…continued support is important, and I think… it could come in waves, because I think it has to be ready.”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
		Developmental Checkpoints for DCP		Proactively offering information or support at relevant developmental stages or predetermined points across the life course.	11	“Like, we have charts for our car. They say at 30,000 miles, you have to have your oil changed, and your filter done, and this and that. It would be great if there was not necessarily mandatory, but within the healthcare system, once you know a child's donor conceived. That at age 8 "this should happen" at the pediatrician's office. And maybe at age 12 or 13 "this should happen".”
		Re-entry at life events		Opportunity to re-access information or support when new needs arise in response to significant life events or donor-conception-related experiences.	5	“just having IVF kids put into her arms, she actually got physically sick. So, you don't know what triggers there are going to be. Further down, you don't know if a good friend is going to have to deal with infertility, you don't know if you hear about somebody else having IVF, what that does to you”
	Continuity of support for Parents			Continued availability of supportfor parents across different stages of donor conception and parenthood.	9	“And it's really only after their parenting and a lot of feelings can come up that I might see them again, and frankly, it's rare. Because they're just so happy to be parenting. So, it's tricky.”
		Pre-conception Support		Support and preparation provided to prospective parents before donor conception, including informed decision-making and consideration of the implications of donor conception.	7	“That therapy should start before you make that decision. [...] Ideal state, yes, it would go before even conception.”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	Continuity of support for Donors			Continued availability of support for donors across different stages and experiences associated with donation.	6	"Donors are anonymous. They realize later on, when they are already had their children, and then they regret. So, it's, it's difficult to communicate something that you feel that you made wrong. Or it's even harder if you didn't have it with all the information, or you were vulnerable in that moment, and you make a decision not having all the information in front of you."
		Pre-donation Support		Support and preparation provided to prospective donors before donation, including informed decision-making and consideration of the potential implications of donation.	3	“And I think that if you're willing to donate [...] you have to know the ramifications of that. You're going to have genetic offspring coming from that...”
Professional Competence, Training and Quality Assurance				Knowledge, awareness, specialist training, and formal quality-assurance mechanisms considered necessary to ensure that professionals and services involved in donor-conception-related care are competent, appropriately informed, and responsive to the diverse experiences of DCP, parents, and donors.	32	“I think it would be really, really good if there were also… good training workshops and courses for practitioners to give them the training they need to do it right, because there's a massive dearth in the skill set to support people [...] in the donor-conceived community.”
	DCP-Specific Professional Training			Need for professionals providing specialised support to DCP to receive specific training on donor conception and the experiences and needs of donor-conceived people.	5	“All of our, you know, all of our social workers, all of our assistants always end up being people who are trained in adoption trauma. But they're not really trained in this, and while there's a lot of overlap.”

Parent Code	Child code	Child code2	Child code3	Description	References	Example
	General Health Professional Awareness			Awareness and understanding of donor conception among healthcare professionals sufficient to respond appropriately and signpost when necessary.	5	“I am giving lectures to pediatricians, to GPs, [...] to all kinds of professions, to make them realize what the implication is of donor conception [...] I think we should be… people should be aware of research [...] so that we base our advice [...] on research, not on my opinion or personal view.”
	Quality Assurance			Standards, qualifications, accreditation, certification, or other mechanisms for ensuring professional and service quality and competence.	3	“I wish there was, like, some sort of certification, like, this therapist has been DCP certified, like, they know the best practices, the, like, evidence-based research, like, best practices, and it's, you know, this person I can go to, and they'll directs me to all of these correct resources.”