Consultation Report

Donor Conceived Register Registrants Panel's proposal to establish a new peer-led organisation. Responses, findings and recommendations.

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Co-Chairs DCR Registrants Panel
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“Write what should not be forgotten.”

-Isabel Allende

Acknowledgements

This report would not have been possible without the wealth of knowledge, insight and support shared by so many people. All of whom we look forward to working with closely in the future as we establish Donor Conceived UK. So a huge thank you to everyone from the Donor Conceived community who answered a survey, submitted a response via our website, attended one of our meetings either in person or online or who communicated their thoughts, hopes and experiences with us another way.

Foreword

In the car on the way to school. In your parents' study, helping them clean out old papers and move house. On your 18th birthday. During your parents' divorce. At work reading the results of the AncestryDNA test you did for fun. At the funeral of one of your parents… or just always knowing – every donor conceived person can tell you exactly where they were when they either discovered or they fully understood what it meant to be donor conceived. Discovery in itself is of huge significance to many donor conceived people, but many find it is only the beginning of a journey that propels their lives onto trajectories they never conceived of.

We are Lauren and Aimee, two donor conceived people (DCP) from Australia. Despite learning our truth of being DCPs in very different ways and decades apart, our own personal watershed moments have been strikingly similar. In meeting other donor conceived people who 'got it' and validated our feelings and perspective, we learned about the power of community in creating a movement that can lead to big change. Connecting with others who helped give us our voice started us on a completely new path of self-discovery and advocacy that continues to this day.

Along the way we discovered that the most powerful paradigms we need to challenge are the ones that are invisible, that are taken as self-evident. As donor conceived people, we are often conditioned to view ourselves within the narrow constraints of language and narratives defined by others: A miracle baby. A gift. Cutting edge science. A product of a globally profitable industry.

This report is a collective watershed moment for the UK donor conceived community. Within its pages it says, 'your voices, your stories, your truths are valid, and deserve to be at the forefront of research, media and policy.' The peer-led model of support, education and advocacy laid out so beautifully as the three pillars of Donor Conceived UK is about firmly placing DCPs on the path to define your own future. This is an empowering paradigm shift that will change hearts, minds and the law.

The need for donor conceived people to be able to represent themselves has been brewing for a long time and the creation of Donor Conceived UK will ensure governments, regulators, researchers, academics, organisations and the media are able to engage more closely and directly with the community and ensure the voices of DCPs are heard without bias.

This isn’t easy stuff. It takes bravery for a group to come together, and as people familiar with advocacy and community organising, we wish to acknowledge the immense work that went into creating this report. Its existence is testament to a core value that donor conceived people are here for each other. It has been a pleasure to follow and support this work throughout the past year or so from a small ‘embryo’ of an idea to the full report being published today, and we look forward with hope to a bright future with continued collaboration between our countries and organisations and others worldwide.

We build on the work of others. Others will build on our work. From little things, big things grow.

Generously provided by:

Aimee Shackleton, National Director of Donor Conceived Australia.

Lauren Burns, Founding Member of Donor Conceived Australia and author of Triple Helix.

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Executive Summary

The findings and recommendations in this report hope to amplify the donor conceived experience which will in turn make it easier to locate support, expand the offer of resources available and centre the donor conceived voice in policy, research and media.

We want to be part of the solution and don't want to sit around just raising questions and pointing out obstacles. There is a clear need for a peer-led charitable organisation to represent Donor Conceived People and those affected by donor conception practices in the UK.

There is a duty of care for the UK government and the UK fertility industry to acknowledge and champion the recommendations in this consultation report to; acknowledge the relational entanglement legacy left by historical donor conception practices and to ensure the best possible outcomes for donor conceived people going forward.

There is currently a lack of authentic representation for Donor Conceived People (DCP) and those affected by donor conception practices in the UK, both historically and to influence future behaviour and attitudes. The UK DCP community voice needs to be amplified to influence research, policy making, advocacy efforts and to tell the stories of the Donor Conceived (DC) experience. A peer-led charitable organisation can provide a platform for these individuals to share their experiences and advocate for their rights. Whilst pockets of activity have been happening for decades, having an official Charitable Incorporated Organisation (CIO) will strengthen messages and the efforts of individuals with the same aims and vision.

Support and Resources: Donor conception is a life-long intergenerational process and has far reaching social implications. DCP and those affected by DC practices face unique challenges and require support and resources to navigate these challenges. A peer-led charitable organisation can provide understanding, empathy, information, signposting, resources and support for these individuals.

Education and Awareness: There is a lack of awareness and education around the DC Experience. Misconceptions of and minimising of the impact donor conception practices can have in people's lives can lead to poor mental health. The significance of being DC is acute and not always appreciated. A peer-led charitable organisation can raise awareness and educate the government, media and general public about the experiences and needs of DCP and those affected by donor conception practices and can also produce high quality resources to guide people through the DC experience and intergenerational impact.

Advocacy and policy change: A peer-led charitable organisation can advocate for policy change and reform to ensure that the rights and needs of DCP and those affected by DC practices are protected and respected. For example, advocating for everyone to have the right to know their genetic history and encouraging a discussion around birth certificate reform.

Organisation: Overall, a peer-led charitable organisation can provide a much-needed platform for DCP and those affected by donor conception practices in the UK to share their experiences, easily access support and resources relevant to them, raise awareness, centre the DC Voice in research, media and policy and advocate for DCP rights.

The consultation process

The selected research design for this study was born from the idea of ‘imperfect action’. With the Co-Chairs not coming from an academic or research background themselves, the consultation process grew organically from the desire to build a case for the need for a peer-led charitable organisation to represent the UK Donor Conceived Community and those affected by donor conception practices in the UK.

Methodology

Data was collected in a number of appropriate methods such as in-person and virtual consultation meetings, interviews, surveys, observations, conversations, social media polls, and social media discussions over a three-month time period between the end of January and the end of April 2023.

Although hard to quantify explicitly, 60 responses were received to the short survey, 45 website submissions/ email responses to our consultation document, 20+ interviews were conducted over video chat, 15+ 1:1 conversations with individuals over WhatsApp, the online and in-person meetings had attendance of 40+ each, the Facebook chat facility for the consultation had 97 members, polls and questions posed within the Facebook group, with each averaging engagement of between 20-85 people.

The data was largely qualitative and anecdotal apart from the short survey. The sampling is purposive in this study as we needed to gain a deeper understanding of the UK DC Community based on their experience and needs to ensure our findings were representative of this community. As well as UK DCP we also spoke with historical Donors and others affected by Donor Conception practices alongside the DC community internationally, fertility industry stakeholders, experts and Academics.

The findings have been analysed via a mix of statistical, content and thematic analysis to build a case for our proposal to create a peer-led charitable organisation to represent the UK DC Community and those affected by DC practices.

Considering the ethical implications of this study, the vast majority of participants are anonymous.

We know there will be limitations of our analysis due to research inexperience and suggest the findings are received in the acknowledgement that this study was produced in the vein of ‘imperfect action’ and from a desire to make change and serve a community better. It should also be acknowledged that there exists a large number of the DC community who do not know that they are donor conceived but who also require our representation. The stigma and secrecy surrounding historical donor conception practices also means that others may not currently engage with the DC Community (and therefore this study) for fear of being identified or identifying others.

Historical timeline

Such has been the extent of secrecy and lies in the lives of Donor Conceived People in the UK that nobody in authority knew the identity of any UK born adult donor conceived people who could be brought before the Warnock Committee to give evidence of their experiences. The Warnock Report of the Committee of Inquiry into Human Fertilisation and Embryology of 1984 ultimately led to the Human Fertility and Embryology (HF&E) Act of 1990.

Between the 1940's, when Artificial Insemination by Donor (AID) first (but not widely) became available and 1978, when the birth of Louise Brown, the first "test tube" IVF baby, awareness of fertility treatments became more known about in the public arena.

It wasn’t until the introduction of the HF&E Act creating a fertility regulator, the Human Fertilisation and Embryo Authority (HFEA) which introduced some much-needed legal framework around the burgeoning fertility industry. One of the more impactful areas was the requirements for clinics to maintain records of fertility patients, gamete providers (usually referred to as "donors", although most in times past were paid for their contributions and current providers are given expenses) and those born as a result of fertility treatment. Before the HFEA, responsibility for records was solely down to the clinics and practitioners. Most either destroyed their records or did little to no record keeping.

Since the 1990's there had been an uncoordinated movement by a small number of donor conceived people and their academic allies, mostly from the field of adoption, to lift donor anonymity. This worthy aim was not historically supported by the fertility industry, the HFEA or the majority of recipient parents and those wishing to conceive with donor gametes, who often provided hostile opposition. An approach had been made by a donor conceived adult in 1997 to the human rights organisation ‘Liberty', who built a case for establishing identity rights for donor conceived people which was finally brought before the court in 2002 with Dr Joanna Rose and EM, a child (who could not be named because of her age) as joint petitioners. The case established that donor conceived people have as much right to a full identity as everyone else and paved the way for the 2005 legislation by which people conceived with donor gametes after that date would be entitled to full disclosure of their donor parent's identity on reaching adulthood.

Following the historic case, the UK government agreed to fund the register service in recognition that anyone affected prior to legislation being introduced in August 1991 – which included Dr Joanna Rose - would not benefit from proposals to lift anonymity as the law did not cover medical records kept prior to that.

The Donor Conceived Register (DCR), formerly known as UK DonorLink (UKDL), was set up in 2004. In 2013, the running of the register passed to the National Gamete Donation Trust and was renamed the Donor Conceived Register. The responsibility for funding for the register was switched to the the HFEA in 2018 and from 2019 the running of the service transferred again, this time to the Liverpool Women's Hospital NHS Foundation Trust (LWHT). The current register service uses a laboratory at King's College London to analyse DNA test results. It works in a similar way to commercial DNA testing conducted now, except with much reduced and more relevant dataset (being limited to Donors and DCP only) and uses less advanced technology.

The significance of 2023

In 2005 the HFE Act was updated with the introduction of the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511. This caused the HFEA to change its process and level of anonymity for donors. There were two significant changes which changed the landscape of the use of donated gametes:

- The advice and attitude to Donors and Recipient Parents had shifted to one of openness and transparency. Previously, secrecy and denial was the advice given to recipient parents. Because of that, there was little advice or support for the pre-2005 donors themselves – in large due to the assumption that DCP would never know of their origins.
- This was further enhanced when the Equality Act of 2009 came in allowing greater access to fertility treatment for single people and same sex couples. This demographic have also greatly championed

> the message of openness and transparency, accelerating changes to attitudes in family building even further.

The majority of Donor Conceived People conceived after the 2005 law change were now able to access basic identifying information about their Donor from the age of 18. This is their donor's full name, any previous names, date of birth and last known postal address. The first people to be conceived in 2005 reach 18 years old in the Autumn of 2023 and the HFEA is preparing the process of support for those people. This is thought to be 30 in 2023 however, according to the HFEA;

> *"By the end of 2024, around 766 people will be able to request identifying information about their donor. By 2030, this rises to 11,427."*

The interest surrounding this 'Open ID' cohort (although great as it has given the pre 2005 cohort of DCP an opportunity to ride the coat tails of the media and industry interest in the subject with the DCP Community's retrospective agenda) raises concerns from the Donor Conceived (DC) community that this has led to a class system with regards to DCP (and Donors).

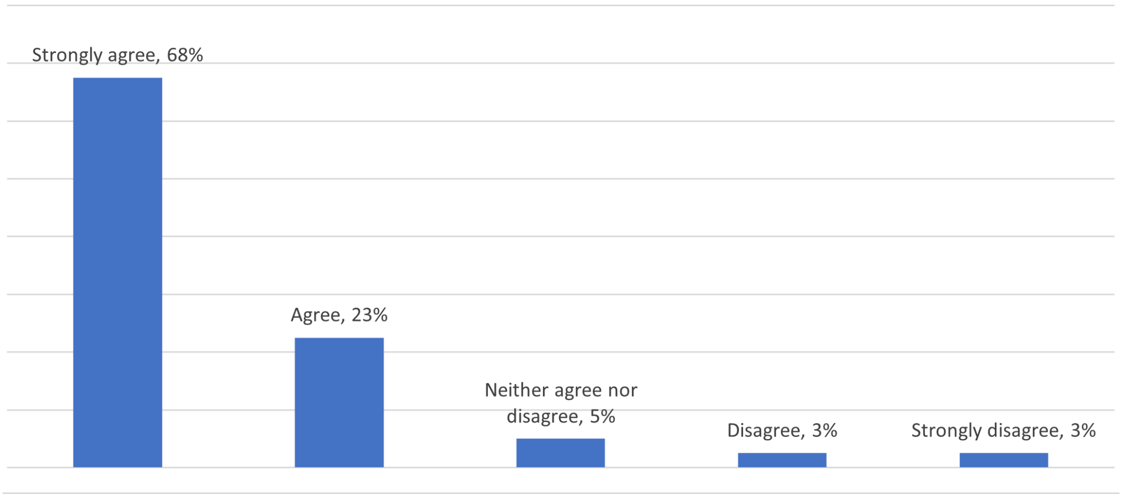
There is now a fragmentation of support, expert and authority bodies with overlapping remit and support with only the DCP community being focused entirely on DCP. This is especially more impactful when you consider that historically (prior to 2005 in many cases and almost exclusively for all prior to 1991) that DCP and Recipient Parents (RP) received advice advocating for secrecy.

Many DCP discover their origins via the use of Commercial DNA Testing. This discovery more often than not results in trauma for the DCP and their social/raising parents, siblings, and other members of the immediate family. It also shouldn't be dismissed that many of the post-2005 DCP will also find their discovery via similar genetic testing methods as parents are not required by law to disclose their offspring's DC status to them - and it is predicted that a large percentage will not know, and therefore will not be aware they can apply to the HFEA for this information.

Identifying a need

The first question in the online survey was,

'To what extent do you agree that there is a need to establish an official organisation with a proper legal structure that is DCP-led and supports, educates and advocates for DCP and those affected by DC practices here in the UK?'



This study has provided overwhelming evidence that a peer-led charitable organisation to represent DCP and those affected by historical donor conceived practices in the UK is long overdue. The response to Question #1 in the short survey demonstrates this trend with 81% of respondents in agreement, which was also backed up by anecdotal support from the DC Community, DCR membership, DCN, charity management professionals, Academics working professionally in the social sciences sector, International DC ambassadors and others affected by DC practices in the UK. As stated by some participants:

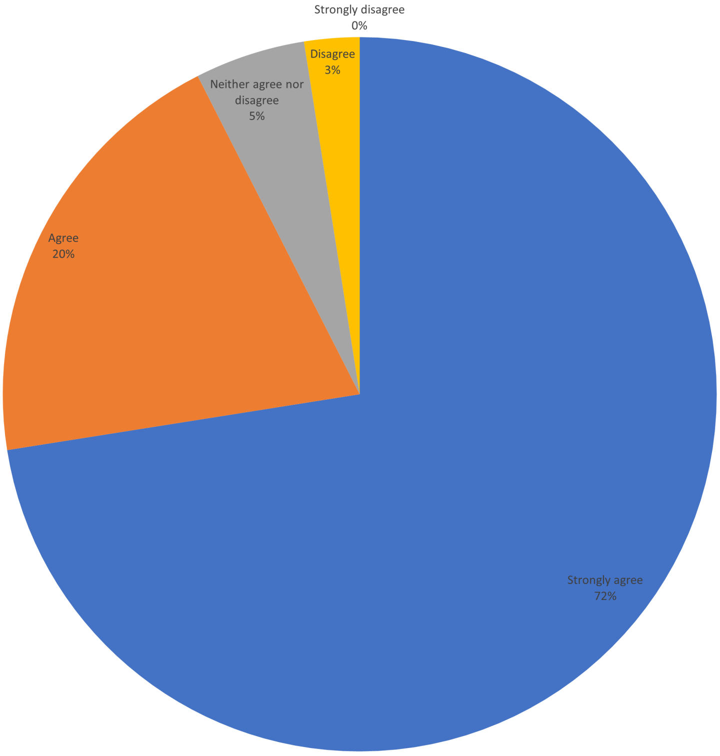
'Thank you so much for everything you are doing, I'm really excited to see the changes brought about by your consultation.'

'I think what you are setting out to achieve will help and support so many people in so many ways.'

'...going forward there needs to be more support for both sides and better education and I feel as a group it needs to be from all sides in order to have a positive and new way forward. It's been shrouded in so much secrecy.'

In the short survey we asked participants to what extent they agreed with the statement,

'The medical intervention that sperm, egg or embryo donation is translated into, does not encompass, forewarn, nor address the long-term relational complexity of the DC experience'



We felt asking this would quantify a generally held view or standpoint for the DC community. 92% of participants either strongly agreed (72%) or agreed

(20%) with this statement demonstrating a need to amplify the DC experience in the public realm.

Although every DCP's beliefs are individual to them alone, it is a commonly held belief within the DCP Community that,

> *'Donor conception is not a medical treatment in the same way that adoption is not. Instead, it is a long-term social intervention.'*

Source: DCR Registrants Panel Community response to HFEA consultation around proposed changes to the HFE Act and Fertility Law, April 2023

Statements such as these can sit at the core of what is built. By identifying and integrating these core beliefs into the discussion around donor conception this universalises and validates experiences for everyone, which in turn will decrease isolation and feelings of helplessness.

We also understand that the experience of being donor conceived is different for everyone and the proposed organisation will allow space to consider and account for the range of meaning that reproductive and genetic connections can have in people's lives. We intend to create a space where all the voices in the mix are TRUTH.

Other statements were circulated as part of the consultation process to spark discussion. The following were decided to highlight beliefs the UK Donor Conceived Community felt important to identify with;

1. 'Honesty is best, not secrecy.'
2. 'There is a need to talk more openly about the issues that evolve logically out of the nature of donor conception.'
3. 'The significance of being Donor Conceived is acute and not always appreciated.'

4. ‘Highlighting the donor conceived experience in the context of what we know about the wider misattributed parentage and adopted community could improve understanding.’
5. ‘Donor Conception is an ethical debate we should be having regardless of technological advancements but not ignoring the impact of direct-to-consumer DNA testing on DCP, Donors, Raising Parents and all their families.’
6. ‘Defacto anonymity ended with the widespread availability of genetic testing but UK laws and regulations are yet to catch up.’
7. ‘Donor conception is a lifelong intergenerational process.’

As well as these statements, the following words feel like they could start to form the ethos for this new peer-led organisation;

Champion

Dignity

Empower

Amplify

This is because the generation living with the impact of anonymous paternity/maternity needs support and a voice. As do the generation of people who don’t know this is their truth. It’s hard to put actual figures on those conceived prior to the 1991 HFE Act and existence of the HFEA. We do know that there have officially been 70,000 such births since 1991 so can therefore assume there are extremely high numbers of people in the dark about their true genetic origins.

We need to speak for the emotional needs and wellbeing of ALL DCP and those affected by donor conception practices who experience the same disruption upon discovery.

The DC generation who has ‘always known’ also need a voice. They have often had a whole lifetime to make meaning of their unique blend of both nature and nurture but may also have a desire to acknowledge all of their parents, both biological and non-biological, without having to minimise any of their contributions.

The current DCP voice is very internally facing. These DCP voices need to be amplified so they can be heard more widely. They desire to search for their genetic origins with dignity and be championed and empowered to do so. The over-arching ‘mission’ statement which sums up the ambitions of this peer-led charitable organisation is to:

‘Enable the best possible outcomes for Donor Conceived People’

The name chosen for this new peer-led organisation is Donor Conceived UK and will use the acronym DCUK, online domain donorconceiveduk.org.uk and social media handle **@DCUK_official**

Further detail on the structure of the organisation can be found in the organisation section of this report on page 44.

What are the ambitions of Donor Conceived UK?

This evolution of the DCR Community into a peer led charitable organisation feels timely. As one consultant participant stated:

‘After years of being a passive community, never wanting to rock the apple cart, to finally challenge and question the ethics of DC practices is long overdue’

It is widely felt that the ‘tide has turned’ on the secrecy element of donor usage and that direct-to-consumer DNA testing has at last given DCP the agency and control to seek the information we need that most people take for granted. As said in 2023 by The Minister for Women’s Health Strategy, Maria Caulfield:

> “I am delighted that donor conceived individuals turning 18 will now have the chance to find out who their donor is. Everyone should have the right to know about their genetic history.”

This growing public awareness (enhanced by the interest in the ‘2023’ cohort of open ID DCP) that DCP morally have a right (even if not legally) and a legitimate interest in knowing their genetic origins, along with affordable genetic testing, has accentuated the impact of Donor Conception practices beyond the triad of Donor, DCP and Recipient Parents.

With a need identified, the following chapters in this report will be arranged into the three pillars of 'Support' 'Education' and 'Advocacy' and will aim to address and discuss the trends highlighted in the consultation process. Some ideas will straddle two or three pillars but having these pillars will help shape the strategy and structure of the future Donor Conceived UK organisation.

The current landscape in the UK

The DCR community Facebook group and website.

There is an existing active and supportive DC Community which has built up around the DCR. This community is managed and organised entirely by the Co-Chairs and other volunteers of the Donor Conceived Register Registrants Panel (DCRRP). An informative website exists at the domain donorconceivedregister.co.uk however there is no formal organisation with a legal structure for the DCP community.

Currently the DCP community primarily connect in a Facebook group where numbers have risen from 255 members in March 2021 to 567 at the time of writing this report (Jan 2024). Advice and signposting is conducted via the website and email.

This community currently shares a name with the DCR which is a DNA database and counselling service currently run out of the Liverpool Women's Hospital NHS Trust (LWHT) and sub-contracted to The Hewitt Fertility Clinic. It would make the community more accessible if it found a new name and created its own brand identity to distinguish itself from the register and its associated service. As a community 'we' are not 'the register'. The community can no longer be described as registrants of the register either as the community is open to anyone conceived in the UK via donor conception practice or historical donors of any era, not just the pre 1991 pre-HFEA time period. This confusion is thought to inhibit easy access to relevant and timely information for newly discovered DCP and overall is a detriment to the community overall – addressing the confusion of the name would be of a major benefit to those seeking support and information.

The DCR is listed on the HFEA website as a 'Partner' and member of the Patient Organisation Stakeholder Group (POSG) alongside 21 other established groups, community and charities, all of which primarily represent the fertility journey. The UK lacks official autonomous representation of DCP both nationally and internationally.

Donor conceived adults sometimes lack and need their own identifiable 'space' to explore this life-long lived experience in its own right. During the consultation process participants told us how DCP voices often feel minimised when our DC status is viewed solely in the context of our parents' infertility or desire for a child. Especially if others minimise/negate/dismiss the importance or significance of the child's unknown biological family. This together with worrying that their parents may be hurt by their curiosity, creates a 'perfect storm' for psychological trauma. All Donor Conceived People should have access to a safe 'space' to consider and process the range of meanings that reproductive and genetic connections can have in people's lives, and what that means for them as an individual.

Donor Conception Network

Representation of the DC voice is often covered by The Donor Conception Network (DCN), which describes itself on their website as,

> '…a supportive charity network of over 2,200, mainly UK-based, families with children conceived with donated sperm, eggs or embryos, those thinking about or undergoing donor conception procedures and donor conceived people.'

Although membership for DCN is free for all Donor Conceived adults, the vast majority of resources, network and event opportunities are not appropriate nor relevant for the majority of DCP. DCN is parent-led, child focused and aims to support the family unit. It does not serve all the complex needs of adult DCP who have been conceived outside of a family dynamic promoting the DCN message of openness and transparency.

After registering with the DCN you receive a weekly email bulletin which includes news, articles and items of interest spanning the whole DCN Community. As a DCP this can at times be problematic to arrive in your inbox as the fertility and family building content is not relevant to the DCP experience.

Upon speaking to DCN we have learned that they are putting in place some changes, as an organisation, which will come into effect once their new website goes live (Early 2024). DCPs will then be re-categorised into a different group, more as 'subscribers' than standard members. They will no longer be receiving the weekly bulletin, but rather something else more suited.

Being a member of DCN as a donor conceived adult also means that you are invited to join a WhatsApp group with the other DCP adult membership. This WhatsApp group currently has 37 members plus a DCN employee representative who, which is worth noting, is also a Recipient Parent. Content shared within this group is moderated by the DCN representative. This is not an especially active or engaged group with an average of one or two posts/discussions every three months. These WhatsApp groups were set up in the Covid period with a view to enabling DC adults to communicate with each other and in the past a few Zoom calls were scheduled specifically for this group. As they were poorly attended, they haven't continued. When asked about the adult DCP offer DCN said:

> 'We use the WhatsApp group and our contacts with families to communicate with DCPs, to invite them to talk at events, contribute to research or talk to the media, so that their voices can be represented. Our hope is that the new DCUK could continue to foster those relations and offer the voices of DCPs at our events to inform parents and would-be-parents of their experience.'

As it stands, the Co-Chairs of the DCRRP Laura Bridgens and Roy Davis have a good relationship with the DCN, who share their belief that DCPs need their own autonomous organisation to champion their needs as an entity of its own which was encouraged when Freddie Howell was chair of the DCRRP and DCN has continued to support this notion.

The evolution of the DCR community into an official peer-led organisation can only enhance the 'authenticity of message' in appropriate collaboration between the two organisations whilst allowing space for the scope of their differing agendas. There is easily room for both to co-exist, and both are required to fulfil the needs of their communities.

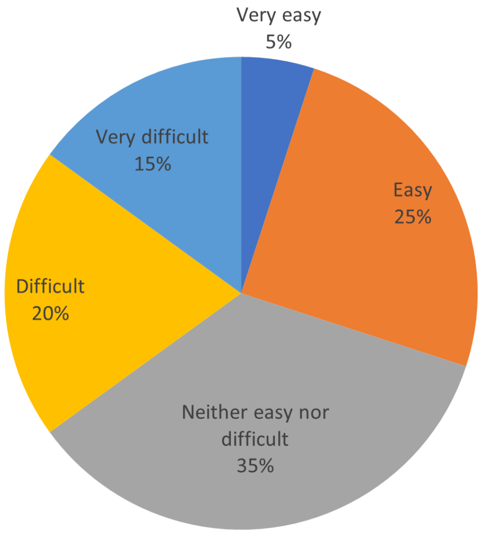
> “I tried to reconcile the splintered pieces of my identity but there was a problem. In the place where I had inherited half my genes all I could see was a void. By extension I felt part of that void, hollow and empty. I was plagued by a terrible sense of dissonance, fragmentation and desynchronisation, like time itself was standing still. I couldn’t make sense of my past, which jumbled my present and clouded my future. My internal narrative, the building block of the self, was confused. I couldn’t reconcile the story shaped by my birth certificate and upbringing with the story of the DNA unfurling within my cells.”
>
> -Lauren Burns: Triple Helix (2022),
> University of Queensland Press

Support

Learning you are donor conceived often creates a lot of questions without answers causing strain on mental health and well-being. This chapter will not spend much time demonstrating why it’s important for donor conceived people to know their genetic origins as current regulations and attitudes in the UK encourage ‘openness and transparency’ but will instead focus on the support needs of DCP and those affected by Donor Conception practices in the UK regardless of the era in which they were conceived.

As a community we are already doing a lot of this ‘support’ really well. Time and time again during the consultation process people mentioned how much they value the peer-to-peer support available in the DCR Community. Signposting needs improving (which will be helped by the creation of a new peer-led organisation) so that all DCP, historical Donors and others inter-generationally affected by DC practices can find the help, support and resources they need easily. The points worth noting here are that over one third of participants who answered the short survey found it either difficult or very difficult to find the support/resources they needed to manage their personal DC experience. At the other end of the spectrum another third found it either very easy (5%) or easy (25%). We also undertook an experiment ourselves which can be found in Appendix A to demonstrate a typical user journey from common online search terms. Many of the participants spoke of not knowing the correct terms such as 'donor conceived' which also acted as a barrier to support. For example, prior to the 1990's donor conception was widely known as Artificial Insemination via Donor (AID).

How easy was it to find the support/resources you needed to manage your personal DC experience?



Two of the main threads that came out of the consultation process around the subject of support were to:

- Embed a strong mental health presence in the new organisation. This is also considered the most likely route to funding.
- Expand on the support offer available.

We are hearing that this community needs something systematically different. Whilst still recognising the value of 1:1 counselling; we have ambitions for a raft of multidisciplinary tools, resources and peer-led events both virtually and in-person.

Talking therapies alone may not be enough to help people heal deep emotional wounds and a more holistic approach may be necessary. Some examples that could be integrated into both clinical and self-care practice include meditation, walking, breath work and creative practices such as writing, drumming, dancing and painting.

On the other hand:

Talking therapies may also only be required short term with support looking different longer term.

Looking first at those who may need a more dynamic approach to healing, The Liverpool Women's Hospital website states that the DCR Counselling service was set up 'in recognition of the complex emotional and psychological issues which arise from new findings about your origins and the DNA testing process'.

Exploring deeper into what these complex emotional and psychological issues might look like, a common definition of psychological trauma is:

'A normal reaction to an abnormal situation.'

Many aspects of the DC experience can be categorised as traumatic experiences.

When we ask the (left hand) logical part of the brain to tell their story, we are asking them to go to the wrong side of the brain. Trauma is stored visually and viscerally and to access this trauma right hand brain modalities must be used (Adamson Holley 2021).

It is possible to treat someone with trauma and never say the word 'trauma' but it is imperative that trauma research is considered when planning for support needs for DCP and others affected. It all comes down to survival response in its simplest terms. A lot of these behaviors are rewarded in UK society. We all live in a society where we are not supposed to talk about traumatic things happening. Recognising the call to 'Keep Calm and Carry On' causes us to minimise a problem and normalise

certain experiences. The brain and body will have made these adaptations but is that serving us well?
It needs to be made as easy as possible for people to find support and community from people who have lived experience. It can be lonely and isolating to be donor conceived when you're searching for answers, for closure, for new beginnings, for acceptance, for our experiences and feelings to be validated. The impact of rebuilding an identity after a discovery like this also needs acknowledgement. It is lifelong.

'I am one of the fortunate ones but even in the best-case scenarios there is so much grief'

'Just because we may have had a nice life before our surprise, it does not make the surprise any less painful or confusing or whatever we may be feeling'

There needs to be an acknowledgement of the need for a necessary mourning period to cleanse the mind and to make room for whatever may come- A space where all of a DCPs emotions are valid and their experience is not minimised or eclipsed by the context of their parents' infertility or their desire to have a child. This is why a richer community with deeper connection and greater resources is required. Recipient Parents may not be able to support you if they are in denial, or friends might not understand the gravity of your situation, you need to be able to build that 'back up' support with people who DO want to understand your struggle. DCPs and those affected by Donor Conception practices in the UK need to share what's happened to them and reach out to others in the community. As one consultation participant puts it,

'Although we have different responses to being DCP, almost none of our experiences are without some hurt or sorrow. Especially if you already

struggle with mental illness. We just have to KEEP GOING. Our identities are shaken like an etch a sketch, but with time, who you are and who you want to be will emerge again. We all have identities outside of our hereditary and also an inherent value and a right to be here and belong.'

For those who don't believe they require counselling or other therapeutic treatment they may still find huge value in a peer-led support community made up of those with the same lived experience and those who have walked this path ahead of them.

Creating and maintaining the infrastructure for a safe space and helping people feel seen and heard is invaluable to guarantee stability for the **Donor Conceived UK** community moving forward. This infrastructure needs to be future proofed regardless of who is running the DCR service which has already been passed between various providers in its time.

One salient point which was communicated time and again by participants of this consultation was the need for a safe space that does not include or is led by Recipient Parents. There have never been any Recipient Parents invited into the DCR Facebook group. Current members of the DCR Facebook group held concerns that these proposed changes to the existing DCR Community, evolving to become a more general peer-led DC community, might mean the loss of this active and supportive group staying closed to Recipient Parents. There are no plans therefore to change the demographic of the Facebook group. It will continue to be open to all DCP conceived in the UK over the age of 18 and historical Donors. This is not to say that further Facebook/ WhatsApp groups etc... wouldn't be created as support infrastructure for others affected by historical Donor Conception practices such as raised children of Donors, or historical Recipient Parents.

The Consultation process generated a sense that DCP would be better served and represented by their own peer-led charitable organisation which could then collaborate with the DCN on events, resources and advocacy enhancing the authenticity of representation and enriching the narrative around donor conception practices both historic and for the future.

What should be the aims of peer-led support?

We talk about this new organisation being peer-led but what should be the AIMS of peer-led support? As a community, it is believed they could be:

- Re-centering the DCP Communities voice, rights and stories
- Creating space for the range of meanings that people can put on genetic connections
- Champion the choice of whether knowing one's genetic truth matters to DCP
- Ensuring feelings are not minimised to protect other’s agendas, shame or fear
- Being a stand for others
- Sharing DCP experiences of healing with others
- Reclaiming all that you are and reconnecting with your own roots of belonging

Some of the above aims straddle the pillars of education and advocacy, which naturally happens when support involves empowering, championing or amplifying.

What does Peer-led support look like?

It is also important to outline what peer-peer support looks like on a practical level too. Some of these things are already happening. It is also imperative that support is available and easy to find for historical donors, and others affected by Donor Conception practices.

<u>What we already do:</u>

- Responding to email enquires/ speaking on the phone. That might be advice, support, liaising with LWHT, HFEA or signposting.
- An active and supportive Facebook group
- In person meetings twice a year (currently very London centric)

<u>To expand on the support offer available:</u>

- People's need for counselling is relatively small. What people have told us is that they need access to experienced people that can walk alongside you
- More access to regional and virtual support groups that focus on emotional support, sharing experiences, education and practical activities. To include catering for intersectional DCP groups (LGBTQ+, infertile DCP, Black or BIPOC DCP etc..) Melissa Lindsey in the US seems to be a good example of this
- Under 18s youth support PEER-led (co-led with DCN). It is also noted that the younger generation will look for support in social media spaces, so we need to increase presence on more platforms
- Create a clear calendar of events and opportunities to engage and connect. For example, book groups, healing events and socials.
- Creation of 'buddy scheme' for new members (or anyone really)
- 1:1 support 'mentoring' and 'befriending' (opportunities to meet with someone to talk about how you are feeling or set goals/ intentions)

- Connect with existing organisations such as humanlibrary.org, befriending.co.uk, nationalvoices.org.uk for collaboration opportunities that enable human connection.
- Produce an approved therapists directory
- Produce an approved resources directory

Support themes in the UK DC Community

Anxiety, stress and depression is a real issue in today's world. Layering in a late disclosure, the search, rejection, keeping secrets, being the secret, protecting others feelings or other aspects of the DC experience and this can have a real impact on the mental wellbeing of an individual. Previous poor mental health did appear to be a significant predictor of worse outcomes amongst the participants of this consultation.

Other emotions at play within the community include:

There is often no finality to the DC experience with the possibility of new relatives popping up for the rest of your life. The emotional and ethical labour of DCP having to become non-professional intermediaries and gatekeepers of DC information when this happens also means reliving and revisiting experiences each time too.

Support Recommendations

- The existing Facebook group transitions to being a **Donor Conceived UK** Community support group, with the knowledge that being a registrant on the DCR is part of the service providers 'offer' available to UK DCP and historical donors and is therefore still a relevant topic of conversation in the group and remit of the new organisation.
- The DCR is advertised as a service available for **Donor Conceived UK** Community to utilise
- The community of DCP in the UK is now represented by **Donor Conceived UK**, which includes representation of those registered with the DCR but also those entitled to access information from the DSL and also those DCP able to access Identifying information via OTR from Autumn 2023. The community however will not exclude DCP conceived outside of clinics, but instead via historical 'informal' mediated reproduction processes that have taken place in the UK.
- An offer of future support activity as identified in this report to be led by **Donor Conceived UK** so that it is peer-led and not seen to be mediated by Recipient Parents
- Influence the current HFEA review into future support needs of Donors, Donor Conceived People and their families, in view of expanding the support offer available to DCUK community to ensure there is a breadth of therapeutic and impactful resources available

- Work with partners and stakeholders to improve online signposting to ensure support is easy to find regardless of the era you were born
- The ‘home’ for this community should be this dedicated organisation: **Donor Conceived UK** rather than a ‘service provider’, whilst still retaining links and relationships with the service provider.
- Embed a strong mental health presence in this new organisation ‘**Donor Conceived UK**’
- Create programs designed for people to work through to help process emotions and build resources to cope

Education

It was clear from listening to participants during the course of this consultation, that the area of 'education' is as much about creating or signposting to high quality resources as it is about raising awareness of the 'Donor Conceived experience' in the public domain. This section will therefore discuss ideas and themes for both internal and external narratives, ultimately to assist in enabling the new organisation's mission of,

'Enabling the best possible outcomes for donor conceived people.'

The DC experience needs amplifying to educate public perception around the complexities of being conceived this way. It's all too common for those affected by Donor Conception practices to be offered platitudes which minimise feelings or interpret them in the context of our parents' infertility of desire to have a child. As one participant puts it:

'It's challenging when those around you may not believe you have the need, or right to grieve for a relationship that never existed.'

Grief requires a lot of emotional and mental energy to process. When we experience a loss, we may feel a range of intense emotions such as sadness, anger, guilt or despair. We may also struggle with cognitive tasks such as decision making, memory and concentration.

How people are taught to define family is key in understanding differing reactions. Cultural, societal, familial and personal paradigms colour our understanding of family. Whether we agree or not, expectations are subconsciously echoed in the stories we hear as children and the concepts we see being played out on TV and Movie screens. DC people often hear people speak of how important family is, unless you're donor conceived. Then it's not. It is a belief held by many in the DC community that adoptees typically get afforded more empathy than DCPs do when searching for genetic family.

Why is it important to educate others on this?

For many, family is everything. For others 'family' are those that hurt us the most. Being forced to call someone family can also be traumatic. People create ambient families with people who they love and feel comfortable around. It all boils down to choice. Donor conceived people have lost the right to be able to make that choice for themselves.

All the participants of the consultation had experienced a dismissing of their experience on some level which demonstrates that:

- The subject is still taboo amongst many people
- The scenario appears ingrained on the public psyche from the lens of the donor or recipient parent and there is a lack of DCP stories out in the public domain.

Some commonly heard platitudes/ comments from participants include,

'But your Dad's your real Dad'

'Aren't you glad you're alive?'

'But you must have been so wanted, remember that'

'But are you allowed to track down the donor, I thought it was all anonymous?'

'You're still you / You're still the same person, try and get on with your life'

'Those people are not your real family'

‘It's just DNA’

‘Why open that can of worms?’

When it comes to re-educating others on the donor conceived experience these are some of the themes that participants wished were better understood.

- Feigning disinterest can be a good way to protect oneself and others from disappointment and from the unknown
- Those who have always known or known for a while, may not also be able to raise subject comfortably with Recipient Parents.
- The experience of late discovery and the impact this has on sense of self, identity and belonging
- How family dynamics may change following a disclosure or discovery
- The emotional and ethical labour for DCP when they end up as a ‘gatekeeper’ to donor and half-sibling information
- The lived experience of having so many questions without answers or ‘unfinished loops’
- The instinctive pain of kinship loss
- The psychological distress implications of large sibling groups
- The significance of meeting these genetic relatives, separated through donation, and the ongoing challenges of maintaining relationships of all the affected kin, many of whom are made less ‘visible’ and hence these aspects and people are not given their proper weighting or consideration they deserve.
- Encourage empathy by explaining that we can’t always just ‘get over it’. Especially when you believed something else your whole life’.

- We were not a party to the contract that others signed but effects your life. We want to hold the key to our own genetic truth.
- Quash the view that DCP who have an interest in genetics and biological relatives are problematic, bioessentialist or against LGBTQ. It is worth noting that political boundary lines do not map neatly for DC issues. It is distressing to be labelled as heteronormative for caring about the importance of genetic links that most non-DC people take for granted.
- The topic of donor and DC rights: Privacy is you not telling me something about you. Secrecy is you not telling me something about me.
- Educate on the historical practice of de-paternalising sperm and the concerns over the quality of the informed consent process that a potential donor may have had when considering whether or not to 'donate'. (Beeny 1999)

A couple of participants responses that express the complex experience of being donor conceived:

'Its a dichotomy because I feel both aspects at once; To an extent, I understand my parents thought they were doing what was best for me, and I know that I had a good upbringing and I am loved by my family, but I also feel deep hurt of the lie (or omitting of the truth) by my Mother which makes me feel angry and resentful. I feel deep gratitude and love for my newly found relatives and excitement for the future, but at the same time they feel like strangers to me.'

'Its amazing how many people genuinely think that anonymity evaporates the actual person who hides behind it'

As an organisation we would advocate for acknowledgement, exploration and conversation within a family unit, making sure resources existed to ensure others are supported through processing their own 'stuff' around the disclosure. The donor conceived person themself often ends up with the lion’s share of the emotional burden for everyone the truth affects, without taking the time to allow themselves the time and space to process what it means to them.

> ‘The trauma of discovery is disruptive enough. Carrying someone else’s secret (stone in your shoe) isn’t right “It ain’t the marathon that wears you down Its the stone in your shoe” (Mohammed Ali) To heal, I had to reveal.’
> -Peter J Boni

There is a desire to educate the average person in the street about the DC experience and also historical Donors and Recipient Parents as this will help enable our core mission of ‘enabling the best possible outcomes for DC people’ but there is also a belief that sharing our stories will help people considering donor conception in the future. As quote from Emily Derrick an infertility therapist states:

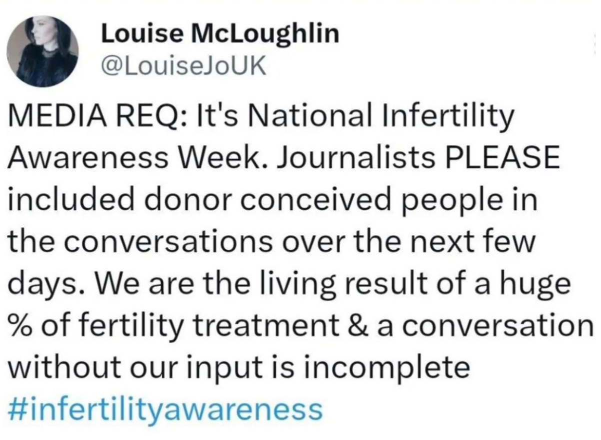
> ‘My biggest piece of advice when talking to prospective parents via donor conception is to hear the experiences of donor conceived people - because babies have a habit of growing into adults. Learning from donor conceived people is one of the greatest windows into the world of your future child. Are you brave enough to look through it?’

Our organisation will enrich the work of the DCN and other ‘fertility journey’ stakeholders and influencers to encourage openness and transparency by amplifying the voices of those affected by historical medical, legal and regulatory decisions ensuring that the retrospective agenda is not forgotten.

2023 has been an extraordinary year for media enquiries but the interest in stories and opinion are very much focused on the new Open ID cohort. From the numerous conversations with journalists and broadcasters so far during 2023 it's clear that educating the media is a role our new organisation needs to take on. When donor conception is reported about, it is common for the donor conceived voice to not be included, the story to be sensationalist or even too light-hearted. It is felt that the human-interest element can be brought into a segment and story, but that the experience can be kept quite surface level and rarely allows for the complexity of the DC experience to breathe. For example, Laura Bridgens Co-Chair of the DCR Registrants Panel, had an experience on Radio 4's The Today Programme where from chatting with the researcher beforehand believed the segment to be focused on the support needs of DCP, but instead the live interviewer went into a level of personal story questions that she wasn't expecting.

Preparing Media Guidelines, which will include how to speak to a DCP respectfully and what the correct language and terms to use, to distribute when speaking with the media, is a priority once our new organisation is established.

Even during awareness weeks and days such as Donor Conceived Awareness on 27th April and National Infertility Awareness Week our community still has to remind the media of the importance of including the DC voice.


Louise McLoughlin
@LouiseJoUK

MEDIA REQ: It's National Infertility Awareness Week. Journalists PLEASE included donor conceived people in the conversations over the next few days. We are the living result of a huge % of fertility treatment & a conversation without our input is incomplete #infertilityawareness

Education Recommendations

- Create Media guidelines document
- Produce a media strategy
- Increase media and social media presence
- Actively develop relationships with journalists, broadcasters and documentary makers
- Hold events or panel discussions with stakeholders to help inform them of our thoughts and feelings
- Learn and educate by:
- Creating high quality resources ourselves and in collaboration with others
- Knowledge sharing materials with and resources with international DC groups
- Create a ‘how to use commercial DNA sites for your search’ guide
- Create a guide on making contact
- Create guides for historical recipient parents, historical donors, others inter-generationally affected by DC practices
- Create content for clinics to share
- Create content for therapists and other mental health professionals to share

- Create a competency based accreditation course for mental health professionals
- Create training for fertility clinic staff
- Create a glossary of terms
- Write and publish books to tell the UK stories
- Educate Doctors and Health Care Professionals, by producing resources and influencing local BMA GP training
- HFEA are increasing the capacity and resilience of the OTR team. We would look to be involved in the OTR's training.
- Encourage improved signposting online and within the sector
- Ensure HFEA and DCR team are signposting to us as a peer-led support option
- Initiate opportunities to speak at relevant events
- Educate the Donor Conceived UK community at events with guest speakers
- Design Publicity Campaign to align with the Donor Conception Awareness day 27th April

Advocacy

There is a lot of injustice in some historical and current donor conception practices. A lot of our community are very passionate about creating lasting change in this area. We do however need to be mindful what messages we are putting out into the world, as these messages will be very important to how our new peer-led organisation is received and/or supported by other people within society and organisations, including those supporting the rights of minority groups.

Recent years have seen developments which support our desire for change. For example, on November 19th, 2019, in front of the UN it was seen that practices both past and present result in the deprivation of the fundamental rights guaranteed by the convention on The Rights of the Child. Including, but not limited to rights conferred by articles 7,8 and 35.

> ‘Everyone has the right to identity, the right to family relations and the right not to be bought or sold in any form.’

These are the rights that the signatories to the convention- literally every country in the world, have a responsibility to protect.

As Right to Know (rightoknow.us) state,

> 'The fertility industry is creating people, not children and we have the right to know any and all genetic history.'

Coming from the belief that the best interests of the human created by the fertility industry be the paramount consideration in any circumstance, pockets of advocacy have been happening for decades. It is hoped that by bringing together those individuals to work together within the structure of a charitable organisation, **Donor Conceived UK** can become a trusted authority in the UK on the donor conceived experience and how to enable the best possible outcomes for donor conceived people.

Alliances and knowledge sharing relationships are beginning to happen internationally. In particular with Australia and USA at this early stage. Developing these relationships is important to ensure that the UK is visible on the international advocacy stage and also that **Donor Conceived UK** exists to be a trusted source of UK specific knowledge.

Recommendations for Creating Lasting Change

During the consultation process the areas participants talked about creating change in included:

- Advocating for the rights of DCP to access information about their origins, medical history and heritage with **DIGNITY** (which overlaps with educating others on the DC Experience)
- Advocate for robust Implications Counselling for intended Donors and Recipients. For example, 1) content should be created with input from people with lived experience of donating gametes a significant time ago (more than 18 years) and also adults with lived experience of being donor conceived. 2) ‘Conflicts of Interest’ should be challenged if internal clinic staff undertake the sessions. 3) An appropriate number of minimum sessions should be implemented i.e. more than one)
- Reforming birth registration law in the UK to include information on both genetic and legal parents on birth certificates

- Removing Donor anonymity retrospectively (like Narelle's Law in Victoria, Australia)
- Seek an official apology (via The Joint Committee on Human Rights) in recognition of the lasting suffering caused by AID/ donor conception practices pre-1991, involving the NHS and the fertility industry.
- Reverse the law that allows freezing of gametes for up to 55 years for the purposes of family building. This is felt too long ethically and not in the best interests of donor conceived people: Having genetic siblings that are potentially 55 years older than them and biological parents that are potentially over 100 years old at date of conception is not without psychological challenges to those affected. Parliament passed the changes to the storage law (under UK fertility law), in April 2022 under the Health and Social Care Act 2022.
- Call for a ban on the importation of reproductive tissue if International clinics involved cannot be held to UK standards.
- Advocate for open ID of Donors from birth (facilitated via clinic), thus ending anonymity
- Campaign to have the UK Donor Sibling Link (DSL) opened pre-18, enabling parents to connect with their children's donor siblings pre 18 on an opt in basis and in a verified way
- Advocate for the option of Donor/Recipient connection on an opt in basis for children already born to open ID donors but have yet to turn 18
- Advocate for funding for genetic testing, screening and counselling for health reasons in the absence of medical history
- Advocate for more presence of DCP as trustees/ board members in fertility industry organisations

Any one of these causes is a huge undertaking but serves to demonstrate the need for a new peer-led charitable organisation to represent donor conceived people, donors and others inter-generationally affected by historical donor conception practices.

Amplifying the DC voice

Day to day activity by **Donor Conceived UK** will strive to influence and centre the donor conceived voice in research, media and policy. One way will be by advocating for more presence of donor conceived people as trustees/ board members in fertility industry organisations. This can also be achieved by attending stakeholder meetings often and engaging with working groups created within the sector. For example the project to produce resources/ materials to prepare historic donors for contact which was funded by the University of Manchester off the back of the ConnecteDNA research project.

Sitting on advisory boards for research projects is also a very valuable activity for people with lived experience of donor conceived practices such as:

The Digital DC research project

The Digital DC (short for Digital Donor Conception) project is a four year, Wellcome Trust-funded research study which explores the practice of informal donor conception (IDC) in the digital age. Laura Bridgens, Co-Chair of the DCR Registrants Panel, sits on its advisory board. It aims to develop knowledge about this growing method of having a family, understand the factors which shape people's views and experiences of it and ultimately improve support and outcomes for those who use IDC and their families.

ConnecteDNA

The ConnecteDNA project was awarded funding by UK Research and Innovation (UKRI) in order to explore how people involved in donor conception both use and are impacted by the rise in commercial DNA testing. Both Laura Bridgens and Roy Davis, Co-Chairs of the DCR Registrants Panel, sit on its advisory board. At the time of writing the project is still ongoing but it is expected to recommend that there needs to be ongoing information published about the broad implications of donor conception practices, follow up support and care for those impacted by unexpected DNA Test results and recognition for the impact on the relatives of those directly impacted as they are often felt they are not considered.

Ultimately the ConnecteDNA study is also expected to address the legacy of historical DC practices, which is important for participants of this study. Their recommendations are likely to complement the proposals made in this report.

DCUK Organisational Structure

The process of this consultation has identified the need for a new Peer-Led Charitable Organisation by evidencing the needs of the UK DCP community and exploring the existing operating environment. It is looking like the best legal structure for us available in England and Wales to individuals or organisations wishing to pursue charitable purposes:

Charitable Incorporated Organisation (CIO).

The CIO is a legal form of charity created in response to requests from charities for a new structure that provides some of the benefits of being a company, but without some of the burdens. CIOs are governed solely by the Charities Commission but have many of the features of a company.Namely they have a separate legal personality and can enter into contracts in their own right. You can also pay people, you would most likely have a CEO and trustees and a plan to build reserves. There is more longevity in a structure like this although the set up will be more involved. We would need to raise £5000 to be able to start a CIO.

We are hoping to be financed by different levels of membership subscriptions and donations from members; from the sale of merchandise, publications and other resources; from income from workshops, events and consulting, Grants, Trusts and Foundations, targeted fundraising and appeals, match funding from companies/ members places of work and crowdfunding.

Individual projects may be eligible for arts, digital or mental health funding for specific activities.

Next Steps

Our next steps are as follows, but not limited to:

- Assemble a ‘Core Team’ or ‘Committee’

The Core Team or Committee required will be made up of 6-10 people.

  - Other Working Parties, 'Teams', will be needed. For example,
  - Marketing / Stakeholder Relations
  - Members / Community / Support
  - Publicity/ Media
  - Legal
  - Fundraising

This Wider Team made up of Working Parties will focus on each of the different areas above. Feedback from each of the different Working Parties will be shared at a Core Team Monthly meeting.

The Wider Community will be invited to quarterly or six-monthly meetings for whomever would like to attend. These will be In-person and/ or virtual. Facebook will be used to share what is going on in the wider Donor Conceived UK Community and get their feedback and insights.

- Create a business plan looking ahead to what **Donor Conceived UK** wants to achieve over the next 1 – 3 years. Once agreed, this business plan will give the committee a plan to work with to help maintain focus and to share with others such as supporters and potential funders.
- Set measurable intentions so progress can be tracked
- Develop activities that will deliver the aims and outcomes we want to achieve.
- Create a budget
- The Business Plan will feature our agreed vision, mission, aims and values honed from the contents of this report, agreed on by the new committee. The starting point for this is a desire to champion, empower and amplify the Donor Conceived UK community to:
    1. Enable the best possible outcomes for donor conceived people
    2. Allow all donor conceived people to explore their origins with dignity
    3. Create a space for the community to explore the range of meaning that reproductive and genetic connections can have in people's lives

These aims are currently expressed as broad statements of intent. The shape and structure of this organisation will centre around three main pillars of support, education and advocacy.

Appendix A

Demonstrate a typical user journey from common online search terms

As the evidence below shows, there is not enough online support that represents UK Donor Conceived People. Also, the signposting to support for Donor Conceived People is practically non existent on the majority of these website.

Several online support links revert to support for Receipient Parents via the HFEA website or the Donor Conception Network.

Online support for Donor Conceived People MUST be far more visible and needs to be better signposted so that "new" Donor Conceived People can find relevant support at one of the most difficult times of their life.

Term: "Conceived by sperm donor"

1. This is the HFEA website which is about supporting donors and recipient parents in the UK, not Donor Conceived People in the UK:

    Preparing for possible contact from someone conceived from ...https://www.hfea.gov.uk › donation › donors › prepari...

    This page outlines what to expect, and the things to consider, if an adult **conceived** from your **sperm**, egg, or embryo **donation** applies to us to access the ...

2. Guardian article which directs to Donor Conception Network which supports donor-conception families in the UKbut in reality supports Recipient Parents, not Donor Conceived People in the UK:

   [At last, Britain's donor-conceived children can know the truth ...
   https://www.theguardian.com › commentisfree › jan › c...]()

   3 Jan 2023 — A culture of secrecy around **sperm** and egg **donations** has given way to greater openness, says fertility consultant Zeynep Gurtin.

3. US & Canadian website:

   [We Are Donor Conceived: Homepage. https://www.wearedonorconceived.com]()

   Donor **conceived** adults share their perspective on **sperm donation**, including how “anonymous” **sperm donation** is a thing of the past. Finding the Lost Generation ...

4. Donor Conception Network which families of donor conceived children with the focus on Recipient Parents:

   [Donor Conception Network | Supporting families through ...
   https://dcnetwork.org]()

   We're a supportive charity network of over 2,200, mainly UK-based, families with children **conceived** with donated **sperm**, eggs or embryos, those thinking ...

5. Research Article from the Center for Bioethcs, Harvard Medical School, US:

   [How Do Individuals Who Were Conceived Through the Use of ...]()

   [https://bioethics.hms.harvard.edu › donor-technology]()

   by R Burke — Approximately 91 percent of our sample were **conceived** through anonymous **sperm donation**, 2.9 percent from anonymous egg donation, and in 80.9 ...

6. Wikipedia entry which has a reference link back to the HFEA website at the end of the page:

Donor conceived person – Wikipedia. https://en.wikipedia.org › wiki › Donor_conceived_per...

A donor offspring, or donor **conceived** person, is **conceived** via the donation of sperm (**sperm donation**) or ova (egg donation), or both (either from two ...

7. European Sperm Bank with emphasis on Recipient Parents and not from a Donor Conceived PERSON's perspective.

   Being a donor-conceived family - European Sperm Bank https://www.europeanspermbank.com › en-int › donor-...

   A **donor** has committed to **donating sperm**, not to playing a role in a child's life. This fact applies to ID release as well as No ID release **donors**. An ID release ...

8. US Sperm Bank article with emphasis on Recipient Parents and not from a Donor Conceived PERSON's perspective.

   Donor-conceived children – everything you need to know https://www.cryosinternational.com › Private › Blog

   18 Jul 2022 — A donor-conceived child is a child conceived with the help of an egg and/or a sperm donor. It is possible for the parent(s) to use a known donor ...

Term: "My Mum was an egg donor"

1. Fertility Clinic Article about the Egg Donor experience:

   Egg donation – who is the mother?

   https://eggdonationcapefertility.co.za › egg-donation-who..

   Is the egg donor the child's mother? The short answer is that if a baby is conceived by an egg donation recipient, the mom-to-be is considered the biological mother of the child in all respects.

2. 2019 Press Article about a Donor Conceived Person's experience of finding her Egg Donor:

   Conceived By Egg Donation – Why I Contacted My Donor

   https://www.refinery29.com › Health › Relationships

2 Feb 2019 — When the woman who raised her passed away, one 21-year-old found out she was conceived by **egg donation**. She told Refinery29 what happened ...

3. Fertility Support website article about a Recipient Parents experience of using an Egg Donor:

   A Mother Shares Her Story of Egg Donation with IVF

   https://www.verywellfamily.com › Treatment › IVF

   13 Jun 2022 — She talks about why she choose egg donation, what the process was like, and how she feels toward both her children and the egg donor. This is ...

4. US Sperm Bank article about a US Donor Conceived Persons experience:

   Experience of being egg donor conceived - Cryos International

   https://www.cryosinternational.com › Private › Blog

   12 Oct 2021 — When researching on IVF treatment, Katie learned that she most likely was conceived with the help of an egg donor. Read her story here.

5. National Library of Medicine research article exploring the relationship of the Recipient Mother and Donor Conceived child relationship, from the perspective of the Recipient Mother.

   "Making the Child Mine": Mothers' Thoughts and Feelings ...

   https://www.ncbi.nlm.nih.gov › articles › PMC7192012

   by S Imrie · 2020 · Cited by 32 — This study explored heterosexual mothers' thoughts and feelings about the mother–infant relationship in families created through egg donation.

6. Donor Concierge article about a Recipient Mother's experience:

Being An Older Mom: My Egg Donation Story - Donor Concierge

   https://www.donorconcierge.com › ... › Blog

   27 Jan 2020 — He was literally a miracle baby. When we learned all that, we had to consider our options. **Egg** stimulation wasn't a good way to go given **my** age, ...

7. Rescripted Fertlity support website article about becoming a Recipient Mother:

[What You Should Know About Becoming A Mother Through ...](https://rescripted.com)

[https://rescripted.com › posts › what-you-should-know-...](https://rescripted.com)

There are several reasons a woman may need donor eggs to become a mother. These reasons may include an infertility diagnosis which results in unsuccessful IVF ...

8. Altruid Fertility clinic article about “Becky Kearns”, a Recipient Mother’s, experience:

[What I wish I'd know about egg donation, by Becky Kearns ...](https://www.altrui.co.uk)

[https://www.altrui.co.uk › egg-donation-advice-becky-...](https://www.altrui.co.uk)

21 Dec 2022 — Catching up with Becky Kearns of Defining **Mum** ... “How do I talk to others and **my** future child about using a **donor** to conceive?

9. Becky Kearns “Defining Mum” blog post about a Donor Conceived Persons experience:

[Q&A with Chloe, an egg donor conceived adult | DefiningMum](https://definingmum.com)

[https://definingmum.com › qa-with-chloe-an-egg-dono...](https://definingmum.com)

3 Apr 2021 — Well I was met with an impossibly low number – unless, an article said, my mother used donor eggs. So I read more and more and it just ...

10. Santa Monica US Fertility Clinic article about whether donor conceived people will look like their Recipient Mother:

[Donor Eggs Epigenetics: Will The Baby Look Like Me? (2022)](https://www.santamonicafertility.com)

[https://www.santamonicafertility.com › blog › donor-eg...](https://www.santamonicafertility.com)

Studies have shown that birth mothers, including women carrying a donor egg baby, can influence such important factors as metabolism and brain development ...

Term: “Support in the UK for donor conceived person”

1. Donor Conception Network supporting donor conception families from the perspective of Recipient Parents:

    https://dcnetwork.org

    Donor Conception Network | Supporting families through ...

    We're a supportive charity network of over 2,200, mainly UK-based, families with children conceived with donated sperm, eggs or embryos, those thinking about or undergoing donor conception procedures and donor conceived people.

2. HFEA article about support and advice as a Donor Conceived Person with links to ALL Recipient Parent websites:

    Get support and advice - HFEA

    https://www.hfea.gov.uk › donation › get-support-advice

    The Donor Conception Network is a supportive network of UK families with children conceived with donated sperm, eggs or embryos, those considering or undergoing ...

3. Donor Conception Network article about the logistics of finding out you are a Donor Conceived Person:

    Questions - Donor Conception Network

    https://dcnetwork.org › donor-conceived-person › ques...

    The organisation that can best help you with personal support and guidance around making connections to others you may be genetically related to or simply other ...

4. Donor Conceived Register (DCR) support page about the logistics of what the DCR is:

    Support | Donor Conceived Regi

    https://www.donorconceivedregister.co.uk › donor-con...

    These provide an opportunity for people to meet other registrants (donor conceived people and donors) and the feedback from these have been really positive.

    5. Manchester Fertility clinic article about Support for Recipient Parents of Donor Conceived Families:

    Donor-Conceived Families: Sources of Support https://www.manchesterfertility.com › Blog

4 Oct 2017 — If you have any questions about having a baby through donor conception, speak to our dedicated Donation Team on 0161 300 2737or book in for a ...

6. NHS Article about Sperm Donation and the law:

Sperm donation and the law

https://www.spermdonation.nhs.uk › sperm-donation-a...

This law allows people who were conceived through sperm donation to find out who their sperm donor was, once they reach the age of 18. This 'removal of ...

7. 7. NGA Law article about the legal rights for egg and sperm donors:

Legal rights for egg and sperm donors - GOV.UK

https://www.gov.uk › legal-rights-for-egg-and-sperm-d...

If you use an unlicensed clinic to donate sperm, you will be the legal father of any child born from your donation under UK law. Egg donors. If you give birth ...

Appendix B

Glossary of terms

‘Open ID’ cohort		A name given to the group of donor conceived people eligible to apply to the HFEA for identifying information about their parents donor once their turn 18.
AID	Artificial Insemination via Donor	Prior to the 1990’s donor conception was widely known as AID
Bioessentialist		The philosophy that biology plays a larger role in determining human psychology or development than social, economic, or environmental factors.
BIPOC		BIPOC stands for Black, Indigenous, and people of colour.
BMA	British Medical Association	The British Medical Association (BMA) is the trade union and professional body for doctors and medical students in the UK.
CIO	Charitable Incorporated Organisation	

Commercial DNA testing		Examples common in the UK are Ancestry, 23andMe, MyHeritage, LivingDNA
ConnecteDNA		The ConnecteDNA project was awarded funding by UK Research and Innovation (UKRI) in order to explore how people involved in donor conception both use and are impacted by the rise in commercial DNA testing. Both Laura Bridgens and Roy Davis, Co-Chairs of the DCR Registrants Panel, sit on its advisory board. At the time of writing the project is still ongoing but it is expected to recommend that there needs to be ongoing information published about the broad implications of donor conception practices, follow up support and care for those impacted by unexpected DNA Test results and recognition for the impact on the relatives of those directly impacted as they are often felt they are not considered.
DC	Donor Conceived	
DC Practices	Donor Conceived Practices	
DCP	Donor Conceived People/ Person	
DCR	Donor Conceived Register. Formerly known as UK DonorLink (UKDL)	
DCR Registrants Panel Community		A name given to the community that has grown around the DCR, that is to be renamed DCUK.
DCRRP	Donor Conceived Register Registrants Panel	The official group meeting held twice a year for the DCR Community. These meetings are chaired and minuted.

Digital DC research project		The Digital DC (short for Digital Donor Conception) project is a four year, Wellcome Trust-funded research study which explores the practice of informal donor conception (IDC) in the digital age. Laura Bridgens, Co-Chair of the DCR Registrants Panel, sits on its advisory board. It aims to develop knowledge about this growing method of having a family, understand the factors which shape people's views and experiences of it and ultimately improve support and outcomes for those who use IDC and their families
Direct to Consumer DNA testing	Same as Commercial DNA Testing	
Donor Conception		A life-long intergenerational process that has far reaching social implications.
Donor Conception Awareness Day		A day to raise the profile of Donor Conceived People on 27th April every year. https://donorconceptionawarenessday.com/
Donor Conception Network	DCN	A supportive charity network of over 2,200, mainly UK-based, families with children conceived with donated sperm, eggs or embryos, those thinking about or undergoing donor conception procedures and donor conceived people.’
Donors		Those who ‘donate’ (or sometimes sell) their gametes (sperm, eggs or embryos)
DSL	Donor Sibling Link	In the UK Donor Sibling Link allows people who share the same donor (donor-conceived siblings) to exchange contact details with one another. It is run by the HFEA.
EM		A child (who could not be named because of her age) who was part of the court case with Dr Joanna Rose who claimed that their human rights as DCP were being breached by being denied access to information about their Donor.

Equality Act 2009		Allowed greater access to fertility treatment for single people and same sex couples.
Gametes		Reproductive tissue: Sperm, Egg or Embryos
Hetronormative		Denoting or relating to a world view that promotes heterosexuality as the normal or preferred sexual orientation.
Hewitt Fertility Clinic		Sub-contracted by LWHT to house the DCR
HFEA	Human Fertility and Embryo Authority	The UK's independent regulator of fertility treatment and research using human embryos.
Human Fertility and Embryology Act (HFE Act)		1990 Act that created the UK fertility regular, HFEA
Intersectional DCP groups	LGBTQ+, infertile DCP, Black or BIPOC DCP	
Dr. Joanna Rose		Was part of the court case with EM (a child who could not be named because of her age) who claimed that their human rights as DCP were being breached by being denied access to information about their Donor.
Joint Committee on Human Rights		The Joint Committee on Human Rights consists of twelve members, appointed from both the House of Commons and the House of Lords, to examine matters relating to human rights within the United Kingdom, as well as scrutinising every Government Bill for its compatibility with human rights.
King's College London		The current register service uses this laboratory to analyse DNA test results
LWHT	Liverpool Women's Hospital NHS Foundation Trust	Service provider of the Donor Conceived Register since 2019
Narelle's Law in Victoria, Australia		Victoria's world first legislation the Assisted Reproductive Treatment Bill 2016 which gave all donor conceived adults the equal right to identifying information regarding their genetic parents.

National Gamete Donation Trust		The National Gamete Donation Service, now known as the SEED Trust, raises awareness of the national shortage of sperm, egg and embryo donors in the UK. NGDT was the previous service provider of the DCR.
National Infertility Awareness week		A week in April to highlight the challenges some parents face when trying to have children.
OTR	OpeningThe Register	This process of accessing identifying information about donors is known as 'Opening the Register'.
Patient Organisation Stakeholder Group	POSG	Led by HFEA it is made up of individuals who represent an established patient group, community, or charity.
Raising, Social, Legal Parents		Recipient Parents who raised the DCP
Recipient Parents (RP)		The intended parents who received the donated gametes
Right to Know		A US charity advancing the fundamental human right to know our genetic identity through education, mental health initiatives and advocacy.
Talking Therapies		Counselling, psychotherapy etc..
Wellcome Trust		The Wellcome Trust is a charitable foundation focused on health research based in London, in the United Kingdom. It was established in 1936 with legacies from the pharmaceutical magnate Henry Wellcome to fund research to improve human and animal health
UK	United Kingdom	
UN	United Nations	

-End of Report-