ARC in 2020 – 2021: a special focus on the impact of Covid-19 on parents and professionals
Receiving unanticipated news in the scan room, or understanding test results that show a baby is not developing as expected, is always difficult for expectant parents.

Uncertainty is unfortunately common when it comes to antenatal screening and its consequences.

Whatever the diagnosis, it is rarely possible to give absolute clarity on the long-term outlook for a baby after birth. Uncertainty is difficult to deal with at the best of times, but during the Covid-19 crisis our parents let us know that when the whole world is an unsettled, potentially frightening environment, pregnancy worries become almost intolerable.

The Covid-19 pandemic heightened and complicated the antenatal screening process.

For safety reasons:
- Women had to attend scans alone. This meant they dealt alone with the shock of news about their baby’s development, and then had to recall complex medical details to relay to their anxious partner.
- Health care professionals were all in masks, making empathetic communication challenging.
- For women making the painful decision to end their pregnancy, Covid restrictions meant they had little choice in how the termination was managed (surgically or medically). For those who were managed surgically, women faced this daunting, hugely emotional procedure alone.

For many couples going through the anguish of bereavement, the first lockdown in March 2020 was welcomed as a chance to escape outside pressures and concentrate on being together. Yet as pandemic restrictions were extended, isolation became more of a strain on worried expectant or grieving couples. Being at home 24/7 in acute grief, or having to attend screening appointments alone, put pressure on even the strongest relationships.

All of these factors led to increased demand on ARC’s support services, at a time when we could not physically staff our national office or deliver face-to-face support groups or professional training. However, we were determined to remain open for all to access our services, and adapted our methods of engaging with parents, healthcare professionals, peer charities, policy and research bodies – via email, call backs, mobiles and continuing to send our handbooks and newsletters out digitally and by post.

This Annual Review explores how ARC helped beneficiaries between March 2020 and June 2021, as well as our broader, consistent support and development during this period. We consider both the immediate effect and longer-term consequences of Covid-19’s monumental impact on antenatal staff, services and families.
ARC by numbers: our impact in 12 months

- Our helpline engaged with 8,540 contacts by phone & email
- Our upgraded online forum provided 4,000 bereaved parents with a safe space to share experiences, feelings & coping mechanisms
- Nearly 60,000 people were reached via social media during our campaign with Tommy’s & Petals, launched October 2020, to raise awareness around termination of wanted pregnancies after prenatal diagnosis
- We trained FOUR new peer support volunteers (Herts, Yorkshire, Surrey, West Midlands) to provide recently-bereaved parents with first-hand emotional support
- 573 families benefitted from our specialist bereavement support services
- 147 students (midwives and sonographers) attended our online workshops specifically for trainees
- 754 healthcare professionals attended our newly converted online training sessions
- Our Director Jane Fisher appeared on THREE podcasts: ‘Time to Talk TFMR’, ‘Worst Girl Gang Ever’ & OpenLearn’s ‘Prenatal Diagnosis & Surrogacy’
Supporting parents

“The PPE, the distancing, the ‘no partners in the hospital’ rules were all necessary and understandable but really exacerbated the painful solitude of the experience. Having to be alone for the initial discovery that something was wrong, then sitting for almost an hour in a small room on my own waiting to be seen by the midwives was agonising... I just wanted to run away with my baby”

Since March 2020, we have heard many testimonies like the above, from parents forced to experience scans, news and procedures alone. ARC, which has always represented a safe, non-judgemental space for anyone seeking support and information, saw a marked rise in all parent services during the pandemic (up from 2019-20 figures – this also includes wider family and friends affected by a screening outcome):

- A 27% increase in telephone and email contacts in 2020-21
- A 14% increase in website traffic
- A 35% increase in the numbers of families seeking specialist bereavement support
- A 16% increase in people accessing our private forum for bereaved parents

As a result, we extended our helpline hours (Tuesday and Thursday evenings) to provide information and support at a time more convenient for those working or with young children. Couples accounted for 60% of this evening service. This enabled both parents to talk to us together via speakerphone: to discuss their concerns, listen to one another when they had differing views and consider possible next steps together. We were also heartened that the pandemic promoted more volunteering requests from those with lived experience of the distress and grief experienced by our parents: our four newly trained peer support volunteer recruits, spread across England, can offer personalised and long-term support.

Pausing our face-to-face parent group meetings, and other forms of physical contact, meant that promoting our services and information on antenatal screening online has been more important than ever. Our social media engagement has increased - particularly on Instagram and Twitter. We’re particularly proud of our joint campaign with Tommy’s and Petals, which launched in October 2020. Raising awareness around termination of a wanted pregnancy after a prenatal diagnosis, this collaboration reached over 50,000 people.

Considering impact: our 2020 survey

Four months into the pandemic, our remote services were already receiving positive feedback. An audit in June 2020 attracted 200 responses, helping us understand what our contacts valued about our service. In the survey, 95% of respondents told us that their expectations of our service were met, and 56% said they were exceeded. ARC’s support is hard to evaluate qualitatively, but survey comments included the following, helping to shape our services in years to come:

“There are insufficient words to express the extent of the comfort given by this service after a TFMR experience. It provided a lifeline and helped me to feel less ashamed and alone. I do not think I would have coped as well as I did without access to ARC’s bereavement support”

“They were extremely helpful with provision of information, compassionate and non-judgemental and extremely, extremely supportive and just listened to me”

“ARC is an amazing charity that supports women through the most incredibly difficult time of their lives. Without ARC I would not have survived”
Supporting professionals

“I’ve just signed up for the August ARC Café... Thank you so much for running these, they’re such a valuable resource”

Gill Harrison – Professional Officer (Ultrasound) Society of Radiographers

The pandemic meant that we had to adapt to remote support and training for the midwives, sonographers, doctors, genetic counsellors and students who usually access our ‘Sensitive Communications’ training in person. As the pandemic developed, there was a growing body of media and sector evidence that medical professionals were suffering both professionally and personally from Covid-19’s restrictions. This echoed the lived experiences shared by ARC’s professional contacts: they were struggling to provide basic maternity care as a result of constant best practice restrictions. This impacted the emotional, medical and ethical complexities involved in this specialist care emerge when participants can meet one another in a relaxed, face-to-face setting. However, online training has some inclusive benefits for our professional attendees – feedback on our support has continued our targetted support in Scotland.

Decades of experience has taught us that frank conversations around the emotional, medical and ethical complexities involved in this specialist care emerge when participants can meet one another in a relaxed, face-to-face setting. However, online training has some inclusive benefits for our professional attendees – feedback on our support has been overwhelming positive and numbers and demographic reach has increased – internationally as well as nationally and regionally. So, whilst we are keen to relaunch our face-to-face sessions in Autumn 2021, we are very pleased that ARC could offer a safe space to share difficult experiences.

Our professional training programme was converted into condensed Zoom sessions (using slides and quizzes, like below, as talking points). These saw a 26% increase in professional attendance (up from 2019-20).

Monthly online ‘Case Cafes’ were a chance for professionals to discuss particularly challenging experiences in a safe and supportive setting.

ARC’s visibility at four conferences meant that both UK and international healthcare workers could learn about our services.

We engaged an ARC co-ordinator for Wales in Jan 2021 to improve our reach to healthcare professionals in Wales, and continued our targetted support in Scotland.

Working in partnership: research and policy

Despite the pandemic’s disruptions and consequences, ARC was able to continue influencing decisions that affected care. We were represented on:

- The UK National Screening Committee (UKNSC)
- The UKNSC Fetal, Maternal and Child Health Reference Group
- The NHS Fetal Anomaly Screening Programme (FASP) Advisory Group
- NHS FASP Information & Education Sub-group
- NHS England Clinical Reference Group for Specialised Women’s Services
- Royal College of Obstetricians and Gynaecologists Abortion Task Force

We also collaborated with peer charities dealing with pregnancy complications and pregnancy loss, always with the joint aim of raising awareness and driving up care standards. As well as our campaign with Tommy’s and Petals, described above, we continued our representation on the core group for the National Bereavement Care Pathway (NBCP) in England and Scotland. ARC sits alongside SANDS (the Stillbirth and Neonatal Death Charity), the Miscarriage Association, BLISS (for premature babies) and the Lullaby Trust (sudden infant loss), to collaboratively developed detailed care pathways for pregnancy and baby loss. This ultimately works to help improve the NHS’s quality and consistency of bereavement care for parents. The majority of trusts in England are now committed to adopting the pathway and audit evidence suggests this is making a tangible difference to care standards. The pathway is currently being piloted by five large health Boards in Scotland, with an evaluation due soon.

In Scotland, ARC’s Scotland Engagement Coordinator continued to work with Glasgow SANDS and Held in our Hearts to co-host support meetings for bereaved parents. These have been maintained virtually during the pandemic.

We were also co-applicants on three important research studies. Valentina, looking at assessing harms and benefits of antenatal and newborn screening in health economic assessments and ACAS (Acceptability of Early Anatomy Ultrasound Screening) were both led by Oxford University. The Great Ormond Street Hospital-led study EXPRESS (optimising the Exome Prenatal Sequencing Service) is a new kind of collaboration for ARC: for the first time we are hosting a Research Associate, Dr Hannah McInnes-Dean, who will also working as an ARC helpline team member. This dual role means that the study will have the deepest possible understanding of how this most sensitive of genetic testing is experienced by parents and what a high-quality care pathway for prenatal exome sequencing needs to include.
ARC in the spotlight

TV: we advised ITV’s Emmerdale on a much-publicised storyline concerning prenatal diagnosis. Our Director took part in the press conference, the BBC’s Woman’s Hour, local BBC stations and ITV’s This Morning.

Podcasts: our Director appeared on three podcasts - Time to Talk TFMR, Worst Girl Gang Ever and OpenLearn’s Prenatal Diagnosis & Surrogacy (the Open University & BBC).

Employee Policy: we were consulted on Channel 4’s new, pioneering Pregnancy Loss Policy – the first of its kind in the UK.

Academic journal: we produced an article for the British Journal of Midwifery on ARC’s work, particularly focussing on the impact of Covid-19 on ARC’s beneficiaries.

Medical publication: we contributed a chapter on ‘Organising Support’ to the forthcoming international Elsevier publication Prenatal Genetic Counselling.

Wrapping up and looking forward & Thank You

The ARC team are currently reflecting on the impact of the pandemic, and how learnings will develop our work in the coming year. We are excited to relaunch some vital face-to-face services in autumn 2021. However, we were delighted that our remote engagement with parents and professionals was successful during the pandemic, offering greater inclusivity, so our services will retain some online elements. In 2021 to 2022, our key priorities are to:

• Redevelop our website and social media tools: ensuring that parents and professionals can easily access information across all platforms and devices

• Improve parent equity resources: developing translations of our publications, and material specifically for LGBTQI+ families and younger parents

• Extend our helpline cover: permanently offering out of hours and weekend cover

• Relaunch our face-to-face engagement: for healthcare professional trainees and parents to meet physically, whilst retaining online alternatives.

Thank you

None of our work would be possible without generous donations from our parents, families and funders, and the encouragement of our peer charities, professionals and policy partners. Thank you for everyone who has donated to ARC this financial year: if you are interested in supporting our 2021-22 priorities, please do get in touch with Katy MacWard (katy@arc-uk.org) or donate via www.arc-uk.org/donate.
ARC’s national helpline
Want to talk? Call 020 713 7486 or email us at info@arc-uk.org

Antenatal Results and Choices
12-15 Crawford Mews, York Street, London, W1H 1LX

Visit: www.arc-uk.org
Facebook: www.facebook.com/antenatalresultsandchoices
Instagram and Twitter @arcantenatal

Registered charity in England and Wales no. 1148653
Registered charity in Scotland no. SC046380.
Registered company 08085949

Annual Review designed by www.carrcreative.co.uk