



Report: a European survey exploring the information and support needs of parents of children with congenital anomalies.

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Summary

Caring for a child with healthcare needs can be challenging for parents and their family. It is therefore important to ensure they are adequately supported. In this research project we aimed to survey parents and carers of children who have structural congenital anomalies (also called *birth defects*) across Europe. We specifically aimed to explore their experiences of information and support, and as the survey was developed during the COVID-19 pandemic, we also included some questions about parents' and carers' healthcare experiences during the pandemic.

We developed a survey in nine languages and asked relevant organisations in 10 European countries to advertise it online and via social media (the Dutch survey was used both in Belgium and the Netherlands). We invited parents and carers of children (up to 10 years of age) who had one or more of the following health conditions to take part: (1) spina bifida, (2) a congenital heart defect which required surgery, (3) a cleft lip (with or without a cleft palate), and (4) Down syndrome. Parents were asked to complete the survey once, which was available from March to July 2021.

In total 1,109 people completed the survey. These were parents and carers of children with a congenital heart defect (n=366), Down syndrome (n=281), a cleft lip (n=247), spina bifida (n=118), Down syndrome with congenital heart defect (n=58), and other combinations of the four anomalies (n=15). Parents and carers lived in Poland (n=476), the UK (n=120), Germany (n=97), Belgium/Netherlands (n=74), Croatia (n=68), Italy (n=59), and other European countries (n=92).

Parents and carers were asked to rate how helpful and how trustworthy they found information they had received from eight different sources. The sources with the highest percentage of 'very helpful' ratings were: support groups (63%), patient organisations (60%), specialist doctors/nurses (58%), and social media (57%). The 'very trustworthy' ratings remained high for specialist doctors/nurses (61%), but declined for support groups (47%), patient organisations (48%), and social media (35%). Nearly half of the parents who were surveyed (49%) reported that they would have liked to have received professional psychological support (e.g. from a psychologist/counsellor) around the time of their child's diagnosis, but didn't receive any. Only 16% of parents reported receiving any professional support. With regards to healthcare experiences during the pandemic, approximately two-thirds of parents in the UK and Poland reported that their child's tests/procedures had been 'cancelled or postponed', compared to around 20% of parents in Germany and Belgium/Netherlands. Around a third of parents in the UK and Poland reported 'cancelled or postponed' surgeries, compared to only 8% in Germany.

1. Background

Congenital anomalies are a range of conditions that occur before a baby is born, and are present from birth^{1,2}. Receiving a diagnosis of a congenital anomaly can be a shocking experience for parents^{3,4} and over time they may experience a number of challenges⁵⁻⁷, such as worry about their child's future health^{5,8,9} or having to leave full-time work to take on additional caring duties³. These experiences can be difficult for parents and it is therefore important that they are supported appropriately^{9,10}. Having access to clear, helpful, and trustworthy information can reduce some anxieties parents may experience when faced with an unfamiliar or complex medical diagnosis¹⁰⁻¹², and support their confidence in managing their child's health condition. Having supportive networks can also be beneficial, such as emotional support from peers^{9,13}, friends and family^{14,15}, and being treated with empathy and honesty by healthcare professionals⁷.

The COVID-19 pandemic has brought new challenges for parents and carers of children with congenital anomalies. In early 2020, most European countries introduced strategies to slow the rate of viral transmission¹⁶. These included the closure of school, travel restrictions, and national lockdowns¹⁷. Increasing numbers of COVID-19 cases put a lot of pressure on healthcare services across Europe, causing severe disruptions to the delivery of care for patients. This was due to healthcare staff being moved to intensive care units, as well as pragmatic decisions to reduce the number of patients attending appointments in hospital¹⁸⁻²⁰. Existing research, conducted during the first wave of the pandemic in 2020, suggested that parents and carers faced many disruptions to child healthcare services, including a high proportion of cancellations to appointments and treatments²¹⁻²³. Parents also reported a lack of support from healthcare professionals, including the absence of specific COVID-19 related guidance for children²³.

It is important to explore the experiences of parents and carers to understand whether their needs are being met, so that healthcare professionals, charities, and government agencies can support them more effectively. In the light of the challenges we outlined above, we aimed to survey parents and carers of children with congenital anomalies in 10 European countries about their information and support needs generally, as well as their experiences during the COVID-19 pandemic.

Aim

The survey investigated the following aims by country and congenital anomaly:

1. Parents' and carers' experiences with information.
2. Parents' and carer's support needs.
3. Parents' and carers' experiences during the COVID-19 pandemic.

2. Methods

Who was the survey open to?

The survey was open to parents, carers, foster parents, and guardians (the term *parents* will be used in the rest of this report), of children with one or more of the following health conditions:

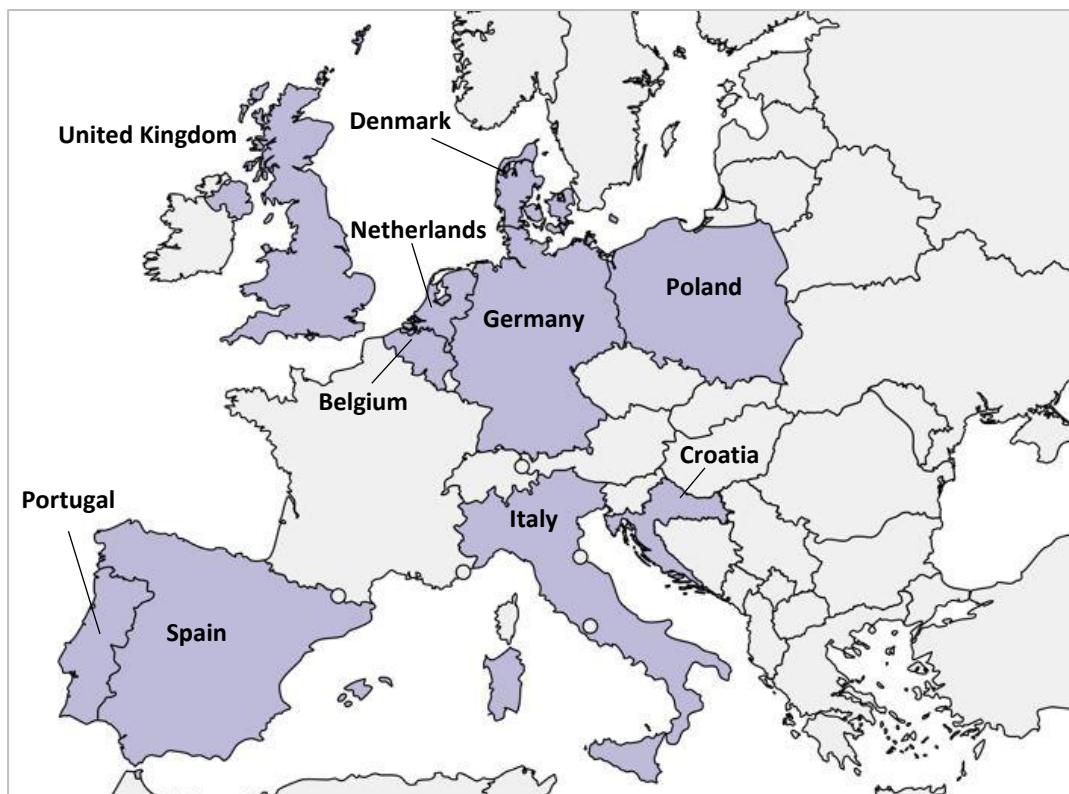
- Spina bifida
- Congenital heart defect which required surgery
- Cleft lip
- Down syndrome

We picked these different conditions as we were interested in exploring different types of “impairments” which we felt may affect the child and their families in different ways. These were as follows:

- Physical disability (spina bifida)
- Learning disability (Down syndrome)
- Visible defect (cleft lip)
- Non-visible defect (congenital heart defect)

We actively recruited parents online in 10 European countries: Belgium, Croatia, Denmark, Germany, Italy, Netherlands, Poland, Portugal, Spain, and the UK (shown in Figure 1). The survey was advertised online via: (1) social media (Twitter and Facebook), (2) patient/parent organisations within each participating country (e.g. the Down Syndrome Association in the UK), and (3) closed support groups on Facebook.

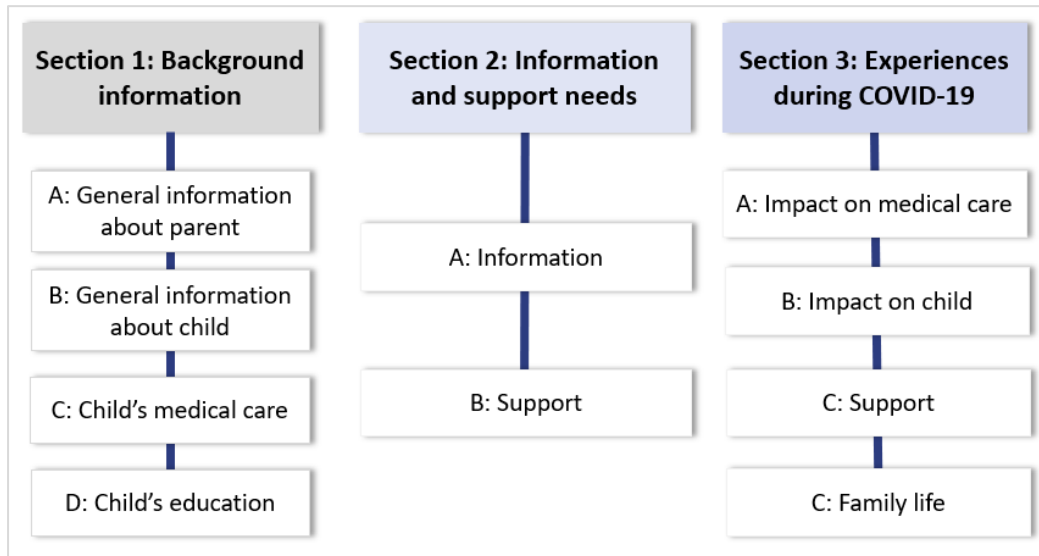
Figure 1 Map showing which countries participated in the study



What did we include in the survey?

The survey was split into three main sections (Figure 2) and included 43 questions in total. All items were close-ended, meaning that numerical data were collected only (as opposed to any written answers).

Figure 2 Overview of the content of the survey



Section 1 (Background information) included questions about:

- Age, gender, country of residence, employment status, education level.
- Child's age and health conditions.
- Free healthcare, which doctors were visited in 2019.
- School attendance.

Section 2A (Information Needs) included questions about:

- Trustworthiness/helpfulness of information received/accessed from various people and organisations (e.g. specialist doctors).
- Overall satisfaction with information received.
- Which topics parents wanted more information about.

Section 2B (Support Needs) included questions about:

- Support from healthcare professionals at time of diagnosis
- Professional psychological support at time of diagnosis
- Satisfaction with support from various people and organisations (prior to COVID-19)

Section 3 (Experiences during COVID-19) included questions about:

- Cancellations and postponements of healthcare appointments
- Virtual appointments (telephone/online)
- Impact of pandemic on child's physical health and emotional well-being

3. Results

A total of 1,109 parents submitted their responses to the survey. Of these, 123 (9.5%) forms were not included in our analysis because: country data were missing (80 parents), congenital anomaly data were missing (24 parents), participants were from non-European countries (4 parents) or participants specified different combinations of the four anomaly types (15 parents).

Characteristics of people who took part

- Most parents were mothers (92%).
- Just over half were aged 31-40 years (53%) and around a third were over 40 (31%).
- Most parents were employed, either full-time or part-time (60%).
- Nearly half had a university degree (49%), and 11% had a post-graduate degree¹.

The number of parents living in each country was as follows:

- Poland – 476 parents
- UK – 120 parents
- Belgium/Netherlands – 74 parents
- Croatia – 68 parents.
- Germany – 97 parents
- Italy – 59 parents.
- Other EU² – 92 parents.

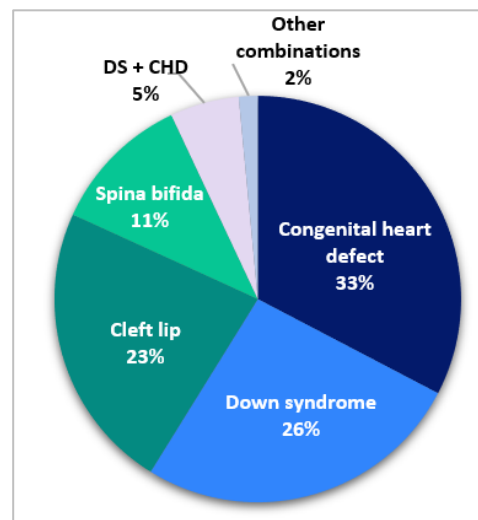
Characteristics of the children

- The most common age category was 1-3 years (35%), followed by 7-10 years (29%), 4-6 years (25%), and <1 year (10%).
- The majority of children were not yet of school age (62%).
- 36% attended school, whereas 2% were either home-schooled or unable to attend school.
- Just of half were male children (56%).

The number of children in each of the congenital anomaly groups was as follows:

- Congenital heart defect – 327 children.
- Spina bifida – 112 children.
- Cleft lip – 230 children.
- Down syndrome – 262 children.
- Down syndrome and congenital heart defect – 55 children

Figure 3 Percentage of children with each of the researched congenital anomaly types



¹ See Table 1 in the Appendix for full characteristics of people who took part.

² Due to low numbers of people recruited in some countries, we created an *Other EU* category for our analysis. This included people from: Denmark (39), Portugal (23), Spain (16), Ireland (5), Bulgaria (2), Albania (1), Cyprus (1), Lithuania (1), Norway (1), Romania (1), Sweden (1), Ukraine (1).

Information needs

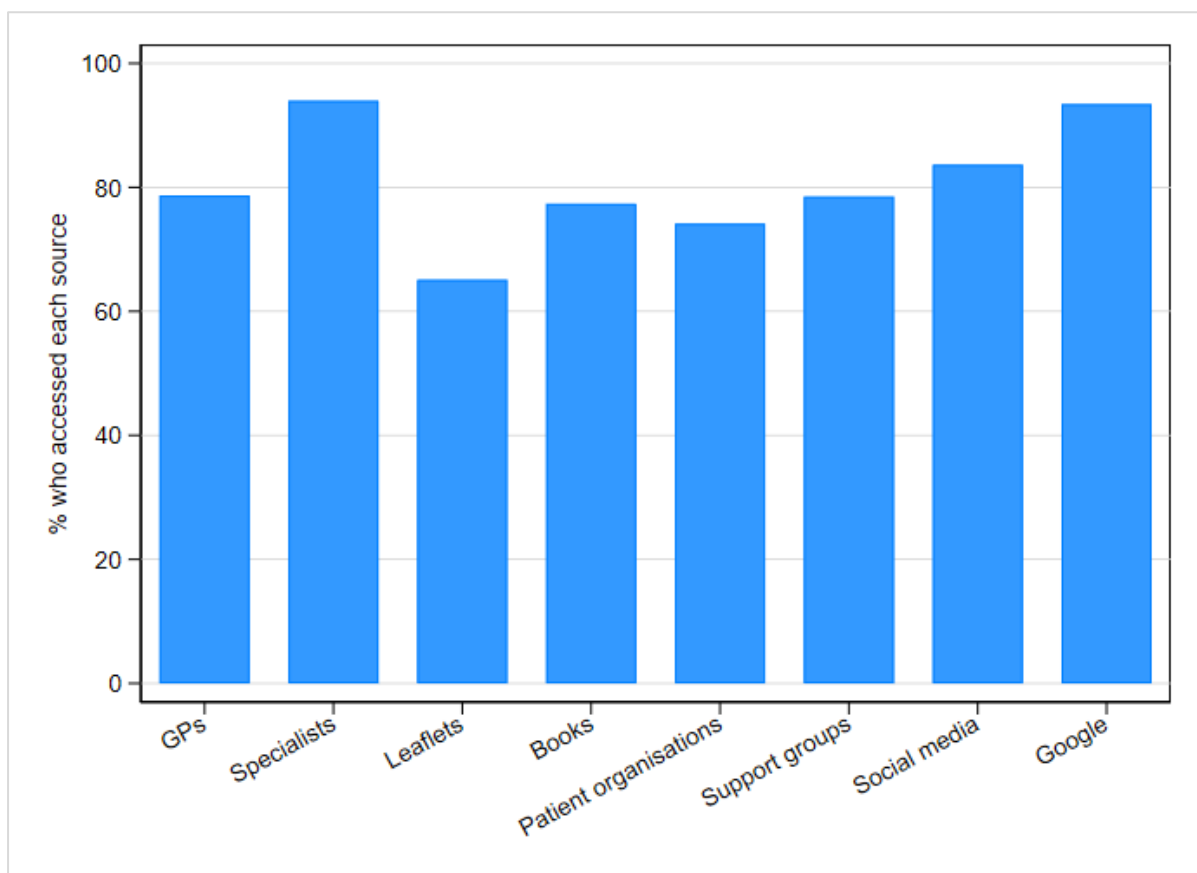
Which sources do parents use to get information about their child's health?

Parents were presented with eight different information sources. These were:

- General practitioners (GPs)
- Specialist doctors/specialist nurses
- Leaflets (from a healthcare professional)
- Books/research articles
- Patient/parent organisations
- Support groups/forums
- Social media/blogs
- Internet searches (e.g. Google)

Of these eight different sources, specialist doctors/nurses (95%) and internet searches (e.g. Google) (93%) were the sources that most parents reported using to get information about their child's health condition (Figure 4). The least popular information source was leaflets/booklets (from a healthcare professional), with 65% of parents reporting that they used this information source.

Figure 4 Percentage of participants who reported accessing information about their child from each source.



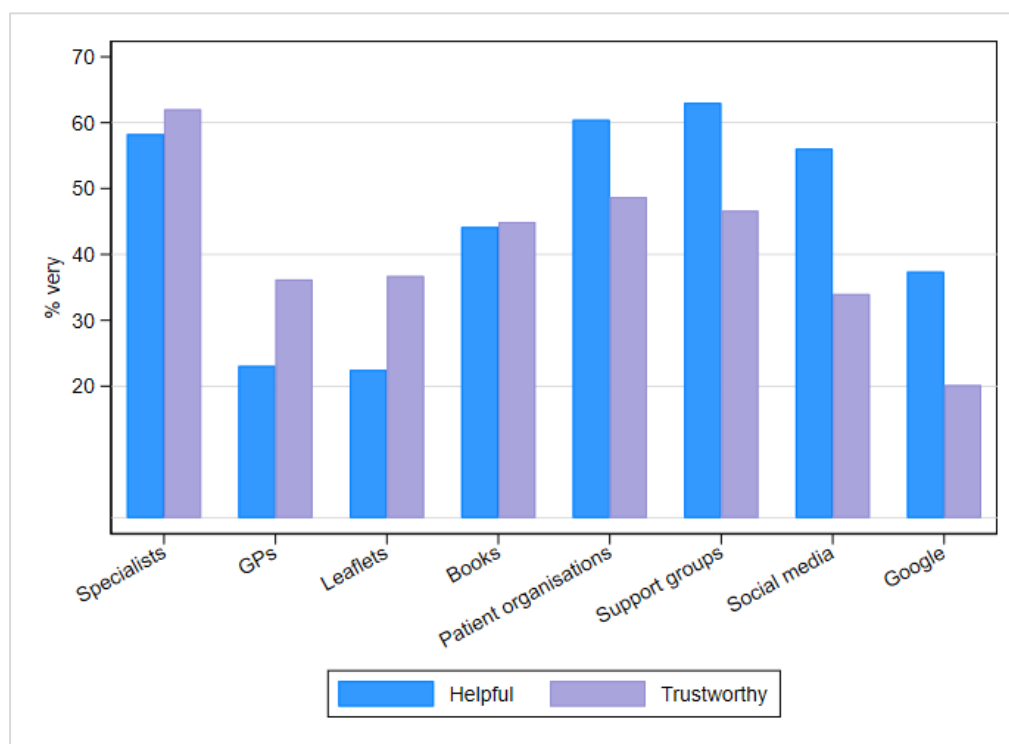
Helpfulness and trustworthiness of information sources

Parents were asked to rate how ‘helpful’ and how ‘trustworthy’ they found the information they had accessed or received from the eight information sources, rating them from ‘not at all helpful/trustworthy’ to ‘very helpful/trustworthy’. We looked at the percentages of parents rating each source as ‘very helpful/trustworthy’.

As shown in Figure 5, the sources of information with the highest percentage of ‘very helpful’ ratings (shown in blue) were: support groups (63%), patient organisations (60%), specialist doctors/nurses (58%) and social media (57%). ‘Very trustworthy’ ratings (shown in purple) were highest for specialist doctors/nurses (62%), followed by patient organisations (49%) and support groups (47%).

Leaflets and GPs had the lowest percentage of ‘very helpful’ ratings, 22% and 24%, respectively. Internet searches had the lowest percentage of ‘very trustworthy’ ratings (20%).

Figure 5 Percentage of participants rating each information source as ‘very helpful’ or ‘very trustworthy’.



Helpful and trustworthy ratings across countries

Parents in Germany, Belgium and the Netherlands tended to rate “medical sources” of information (such as GPs and specialist doctors/nurses) the highest for helpfulness and trustworthiness amongst the countries, whereas for “informal sources” of information (such as support groups and social media) they rated these lower than other countries. In contrast, countries such as Poland and Spain, tended to do the reverse and had the lowest helpfulness and trustworthiness scores for “medical sources” and higher scores for “informal sources”. An example of this is shown in Figure 6 and Figure 7, whereby the Belgium/Netherlands group has the highest percentage of ‘very helpful’ and

‘very trustworthy’ ratings for specialist doctors/nurses and the lowest percentage of ‘very helpful’ and ‘very trustworthy’ ratings for support groups. In contrast, Poland has a higher percentage of participants rating support groups as ‘very helpful’ or ‘very trustworthy’ compared to their ratings for specialist doctors/nurses. Full ratings across countries are available in the Appendix – Tables 2-3.

Figure 6 Percentage of participants rating each information source as ‘very helpful’, by country.

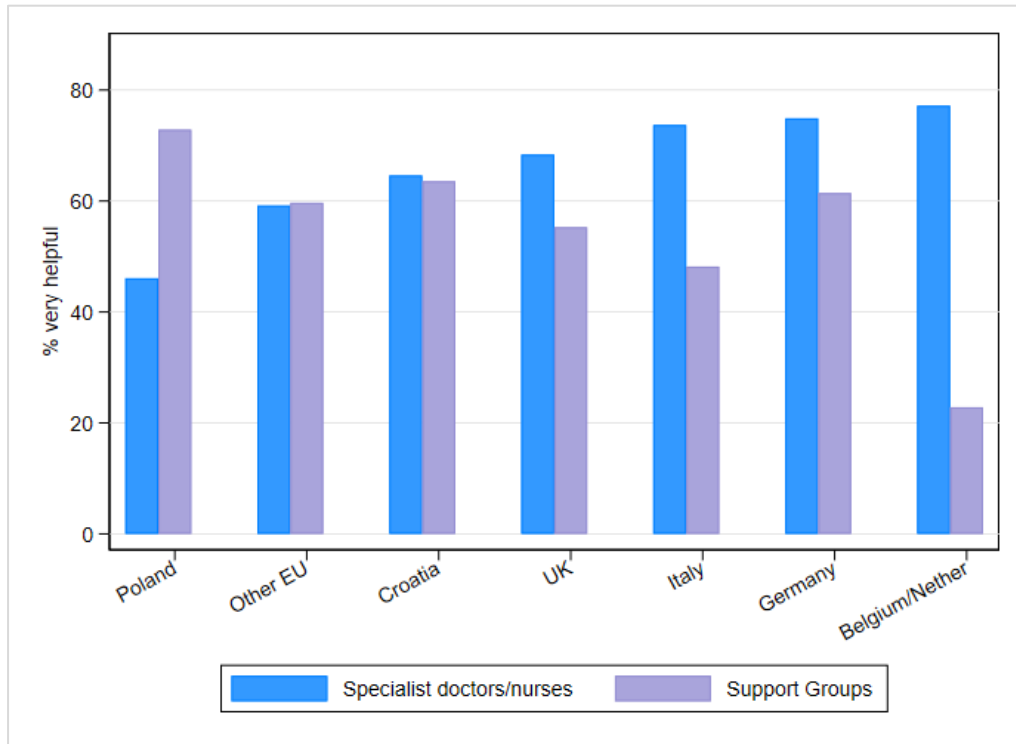
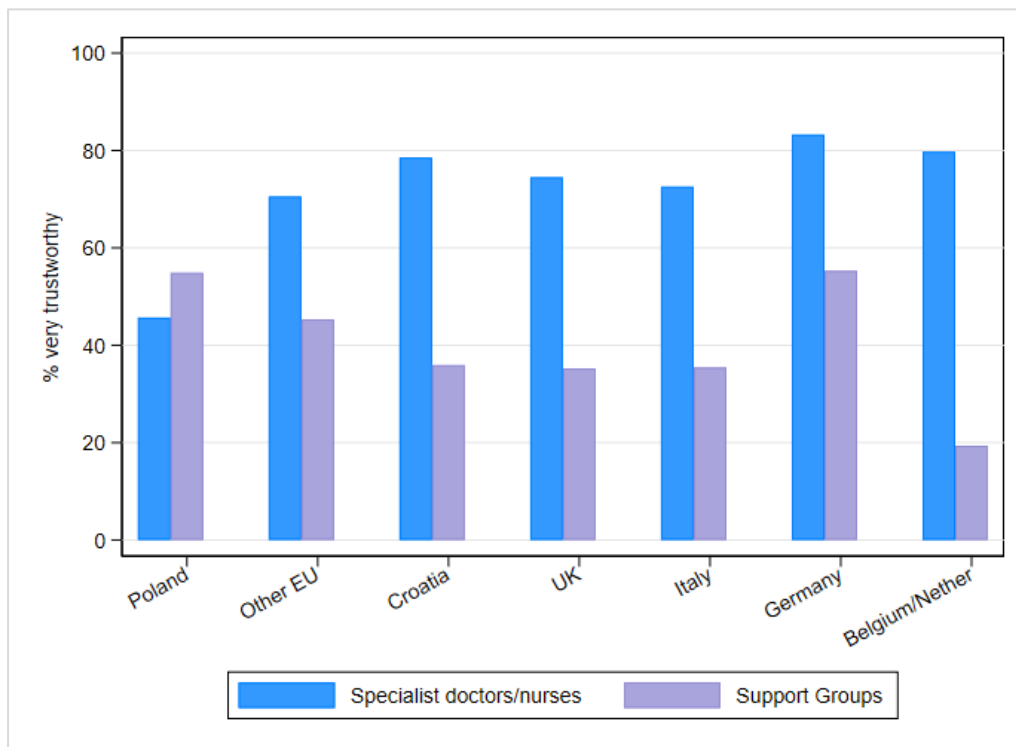


Figure 7 Percentage of participants rating each information source as ‘very trustworthy’, by country.



Helpful and trustworthy ratings across congenital anomaly types

Our analysis indicated that parents of children with Down syndrome were significantly less likely to rate specialist doctors/nurses as ‘very helpful’ or ‘very trustworthy’ compared to parents of children with a congenital heart defect. Parents of children with Down syndrome were also less likely to rate leaflets (from a healthcare professional) as ‘very helpful’ compared with parents of children with congenital heart defect. No other differences were found across the congenital anomaly types.

Satisfaction with information

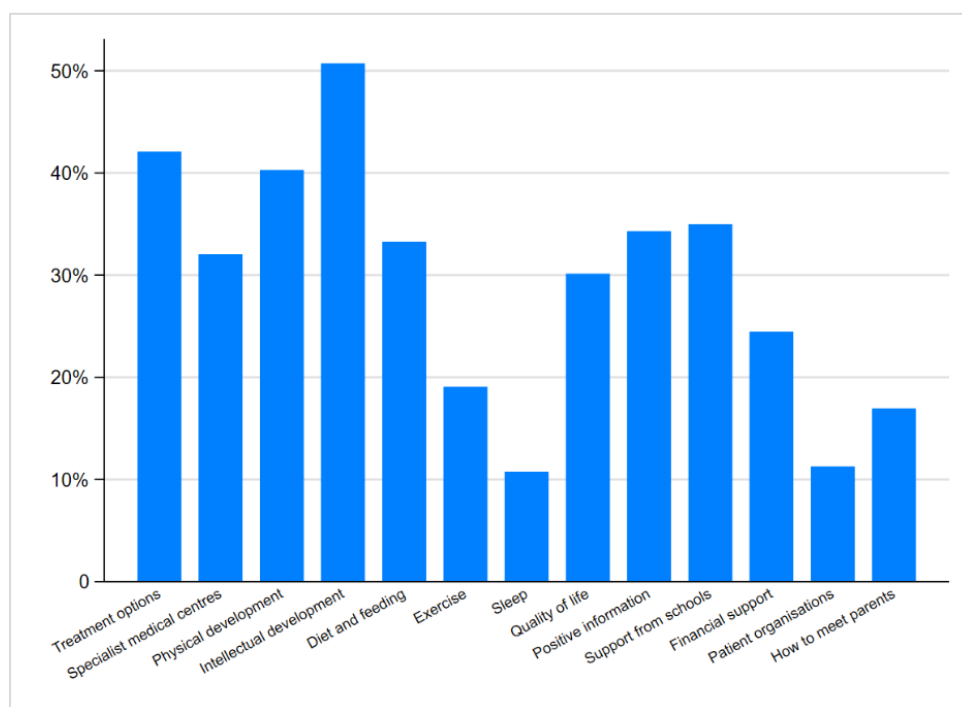
- Overall 23% of parents were ‘very satisfied’ with the information they had received about their child’s health condition.

This figure was lowest in Croatia (11%) and Poland (15%). Our analysis indicated that compared with Poland, satisfaction was significantly higher in Germany (44%), Belgium/Netherlands (38%), Italy (33%), and the UK (32%). In terms of the congenital anomaly type, satisfaction ratings were lowest for parents of children with Down syndrome (13%) and Down syndrome with a congenital heart defect (12%).

Information topics

The topic that most parents wanted more information about was ‘intellectual development’, with 51% of parents picking this option (see Figure 8). This was followed by ‘treatment options’ (43%), and ‘physical development’ (40%). Approximately a third of parents wanted more information about ‘support with school/education’, ‘positive information about my child’s full potential’, ‘diet and feeding’, and ‘specialist medical centres’ (see the Appendix – Table 4 for full results).

Figure 8 Percentage of parents indicating that they wanted more information about each topic



Support needs

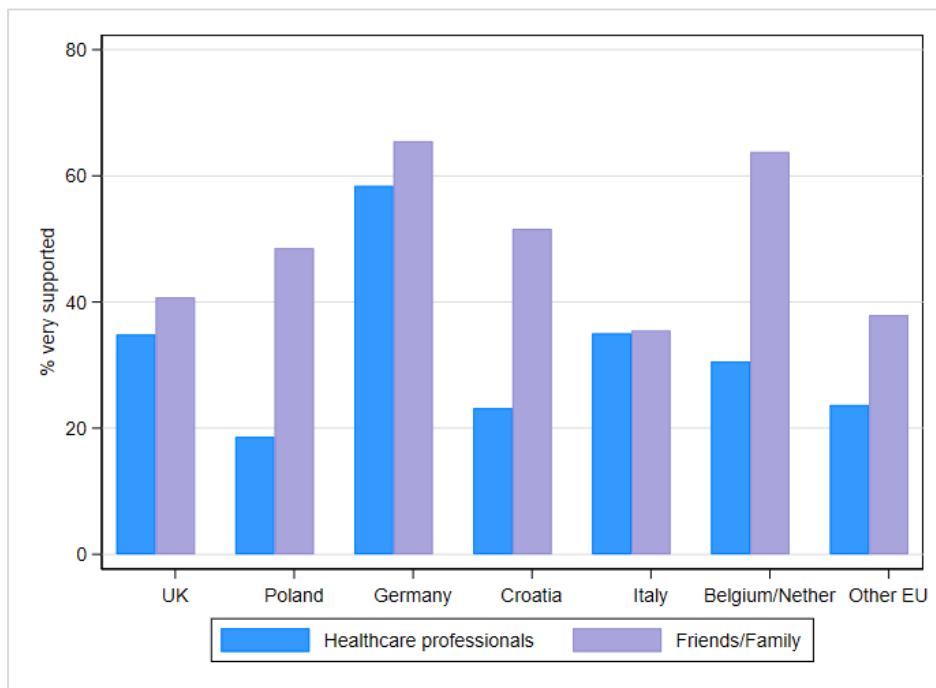
Support from healthcare professionals and friends/family at diagnosis

- 27% of parents reported that they felt ‘very supported’ by the healthcare professionals who treated their child at diagnosis.
- 48% of parents reported that they felt ‘very supported’ by their friends and family at diagnosis.

Support at diagnosis across countries

Figure 9 shows differences across countries in the percentage of parents reporting that they felt ‘very supported’ by healthcare professionals (in blue) and by friends and family (in purple) around the time of their child’s diagnosis. Our analysis found that for ‘support from healthcare professionals’, Germany (58%), the UK (35%), and Italy (35%) all had significantly greater percentages of parents who reported feeling well supported, compared with Poland (19%). For ‘support from friends and family’, only Germany (66%) had a significantly greater percentage of parents reporting that they felt well supported, compared to Poland (49%).

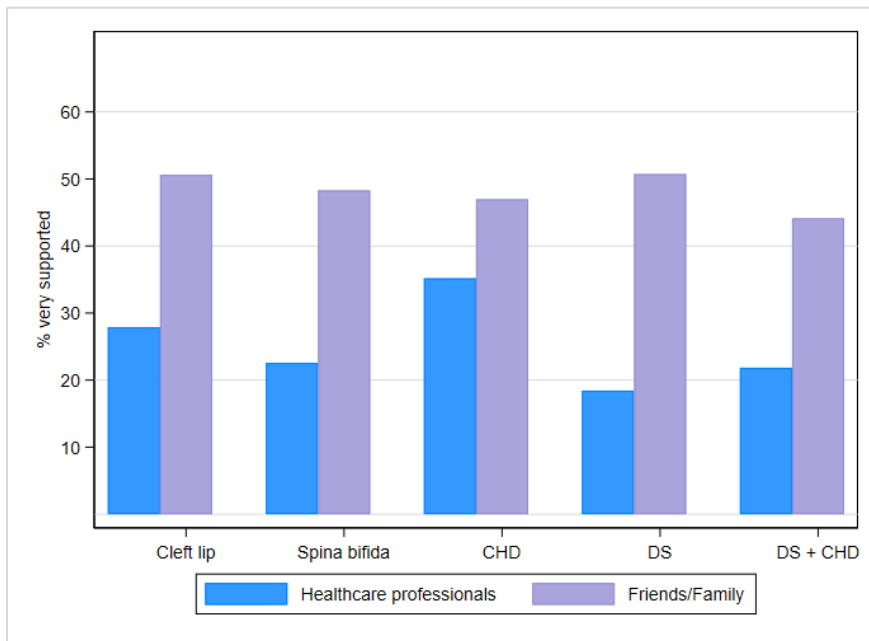
Figure 9 Percentage of parents reporting that they were ‘very supported’ by healthcare professionals and friends/family within one month of their child’s diagnosis, by country.



Support at diagnosis across congenital anomaly types

Overall, as shown in Figure 10, there were few differences in ratings across the congenital anomaly types. Our analysis suggested that parents of children with a congenital heart defect (35%) were significantly more likely to report being well ‘supported by healthcare professionals’, compared with parents of children with Down syndrome (18%). For ‘support from friends and family’, ratings were very similar and there were no significant differences across the congenital anomaly types.

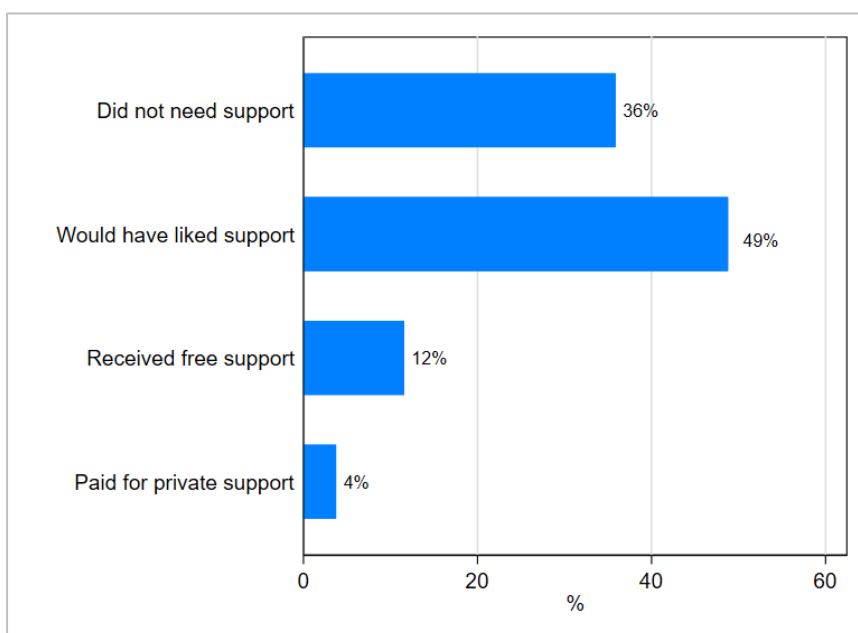
Figure 10 Percentage of parents reporting that they were ‘very supported’ by healthcare professionals and friends/family within one month of their child’s diagnosis, by congenital anomaly type.



Professional psychological support at diagnosis

- 49% of parents reported that they didn’t receive any professional psychological support around the time of their child’s diagnosis, but that they would have liked to (see Figure 11).
- Just over a third of parents (36%) reported that they did not feel like they needed any professional support when their child was diagnosed.
- 12% received free support and 4% paid for private support.

Figure 11 Percentage of participants who reported that they did not need psychological support at diagnosis, those who would have liked support but didn’t receive it, and those who received free or paid support



Experiences during the COVID-19 pandemic

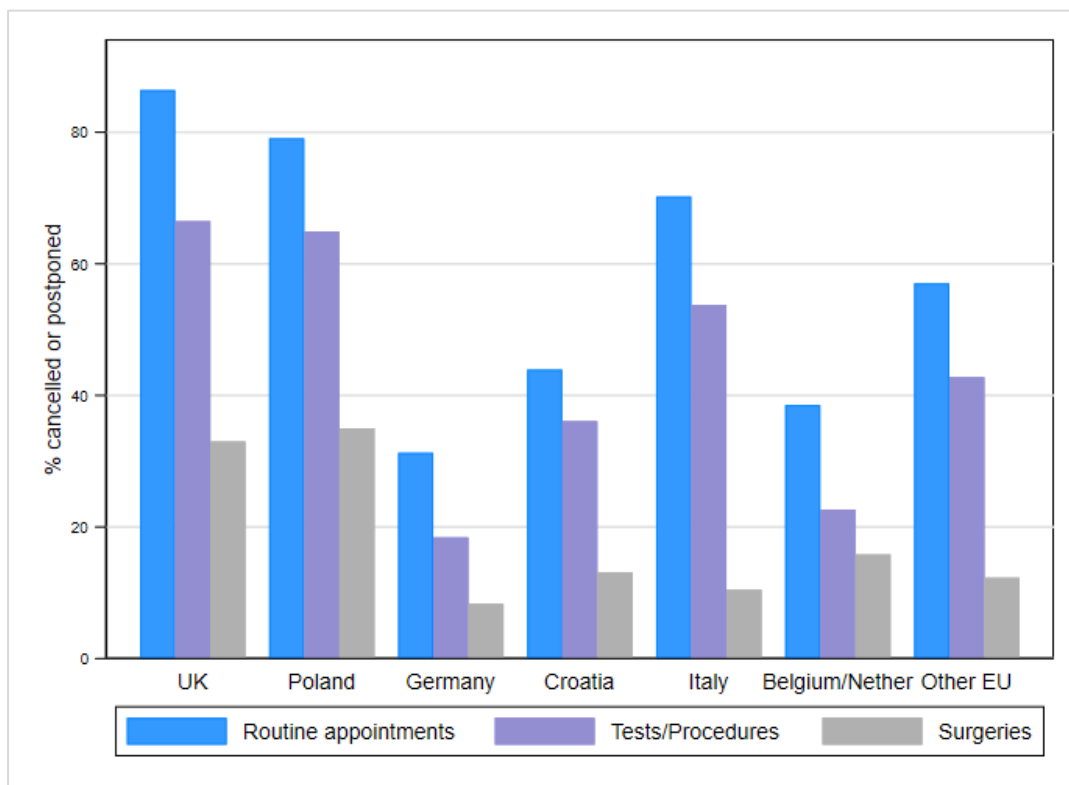
Cancelled or postponed appointments

From the start of the pandemic (January 2020) to the time at which parents responded to the survey (March-July 2021):

- 68% of parents reported cancelled or postponed **routine appointments**
- 53% of parents reported cancelled or postponed **planned tests or non-surgical procedures**
- 26% of parents reported cancelled or postponed **planned surgeries**

The UK and Poland had the largest percentages of parents reporting cancelled or postponed appointments for each category (Figure 12). Compared to parents in Poland, parents in Germany, Croatia, Belgium/Netherlands, and the Other EU group reported significantly fewer cancelled or postponed routine appointments or planned tests/procedures. For planned surgeries, all countries except the UK had a significantly lower percentage of cancelled or postponed appointments than Poland.

Figure 12 Percentage of participants reporting 'cancelled or postponed' routine appointments, planned tests or procedures, and planned surgeries with 95% confidence intervals, by country.



Virtual appointments (by telephone or online)

- 61% of parents reported that their child's face-to-face appointments had been re-scheduled as virtual appointments.
- 29% of parents rated their child's virtual appointments as being of 'poor' quality.

The UK (87%) and Poland (71%) had the highest percentage of parents reporting re-scheduled appointments. Our analysis indicated this was significantly higher than in all other countries. Poland had the highest percentage of parents who rated virtual appointments as 'poor' quality (37%). This percentage was significantly lower in the UK (21%), Belgium/Netherlands (5%), and Germany (0%).

Access to medication

- 26% of parents reported problems accessing medication for their child during the pandemic.

The UK (42%) and Poland (34%) had the largest percentage of parents reporting problems. Our analysis indicated that parents in Italy (14%), the Other EU group (8%), Germany (7%), and Croatia (4%) all had significantly fewer participants reporting problems compared with the UK and Poland.

Impact of the COVID-19 pandemic on the child’s health and wellbeing

- 68% of parents rated their child’s **physical health** as being ‘*about the same*’ as it was prior to the pandemic, whereas 17% rated it as ‘*worse*’.
- 56% of parents rated their child’s **emotional wellbeing** as being ‘*about the same*’ as it was prior to the pandemic, whereas 35% rated it as ‘*worse*’.

Poland had significantly more parents rating their child’s physical health as ‘*worse*’ compared to other countries (Figure 13). There were no significant differences across countries for emotional wellbeing (Figure 14).

Figure 13 Percentage of participants reporting that their child’s physical health was ‘worse’, ‘about the same’ or ‘better’ than it was prior to the pandemic with 95% confidence intervals, by country.

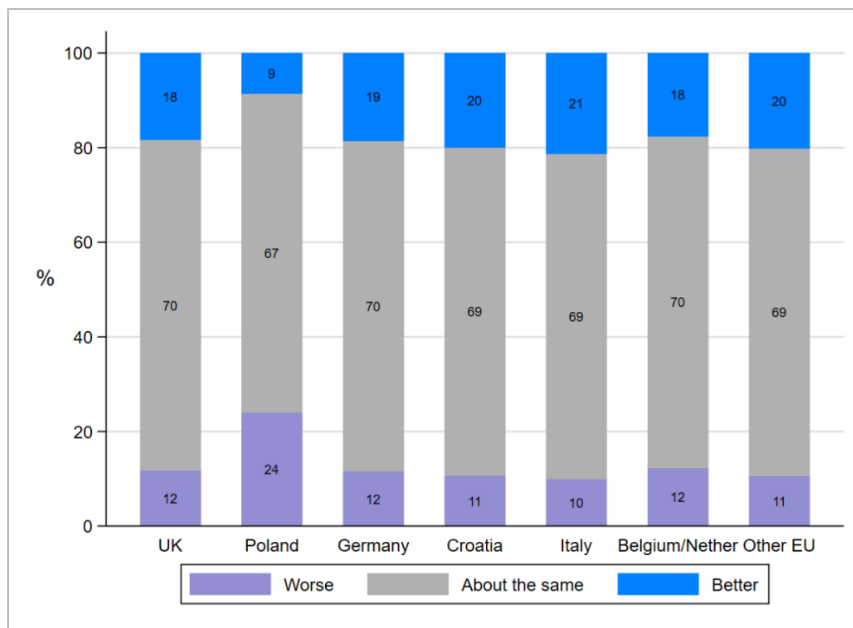
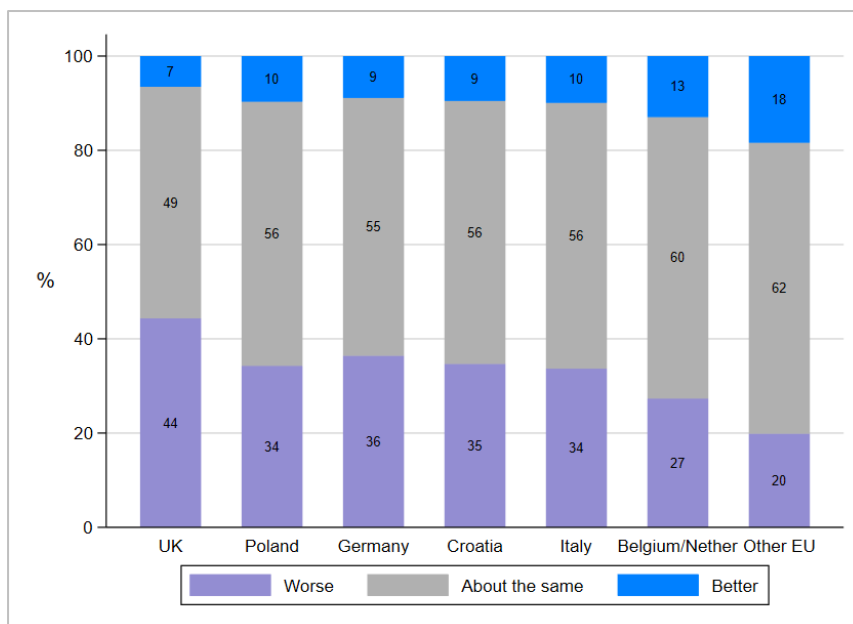


Figure 14 Percentage* of participants reporting that their child’s well-being was ‘worse’, ‘about the same’ or ‘better’ than it was prior to the pandemic with 95% confidence intervals, by country.



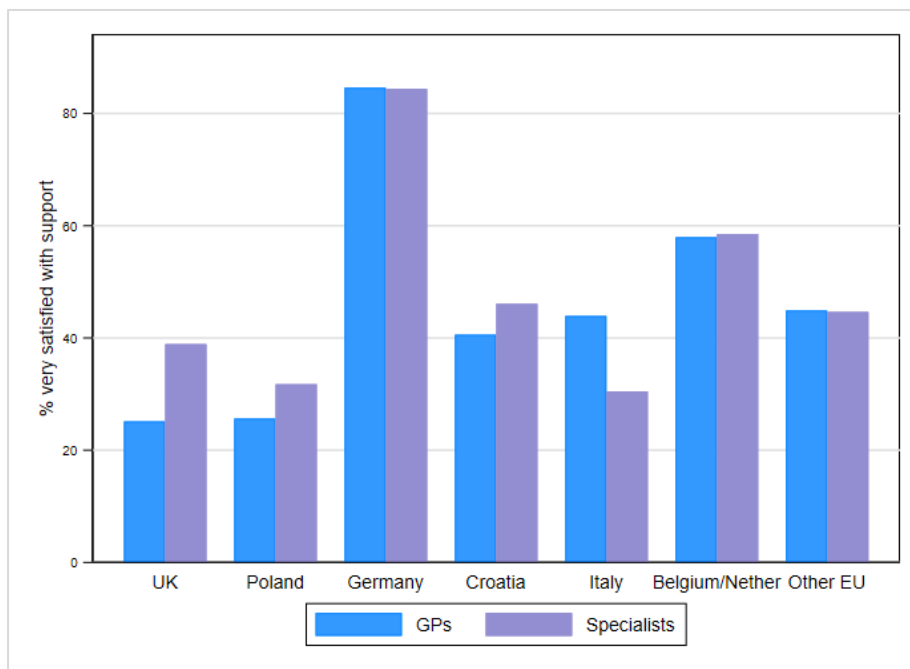
Support for parents during the pandemic

- 23% of participants reported that, overall, they would have liked more support during the pandemic ‘very much’.
- Satisfaction ratings were lowest for support from medical sources and organisations and highest for people that participants had close relationships with (e.g. family).

Support from medical sources across countries

The UK and Poland had the lowest percentage of ‘very satisfied’ ratings for GPs, 25% and 26%, respectively (Figure 15). Italy and Poland had the lowest percentage of ‘very satisfied’ ratings for specialist doctors/nurses, 31% and 32%, respectively. For both GPs and specialist doctors/nurses, our analysis indicated that satisfaction ratings were significantly higher in Germany and the Other EU group.

Figure 15 Percentage of participants reporting that they were ‘very satisfied’ with the support they received from GPs and specialist doctors/nurses with 95% confidence intervals, by country.



Support from organisations across countries

Germany and Poland had the highest percentage of ‘very satisfied’ ratings for patient organisations, 59% and 56%, respectively. Our analysis indicated that compared with Poland, these satisfaction ratings were significantly lower in the UK (38%) and Belgium/Netherlands (14%). The UK had the highest percentage of participants who were ‘very satisfied’ with support from their child’s school (47%), however, there were no significant difference between countries (Appendix - Table 7).

Support from close relationships across countries

Poland had the highest percentage of ‘very satisfied’ ratings for support from parents of other children with the same health condition (66%), significantly higher than the UK (51%) and Belgium/Netherlands (33%) (Appendix - Table 7). There were no significant differences in satisfaction ratings for support from ‘partner’ or ‘friends/family’ across countries.

4. Summary of findings

Our survey found that parents get information about their child's health condition from a range of different information sources, the most popular being via specialist doctors/nurses and internet searches. Informal sources of information (such as social media and support groups) were highly valued by parents, however, medical specialists had the highest ratings for both helpfulness and trustworthiness. In contrast, GPs had very low helpfulness ratings. Overall ratings for satisfaction with information were somewhat low, suggesting a potential information gap.

We found that a large proportion of parents were not adequately supported around the time their child was diagnosed. Nearly half of the parents surveyed reported that they would have liked to have received professional psychological support at diagnosis but didn't, and only a quarter of parents reported receiving a lot of support from the healthcare professionals who treated their child. Prior to the COVID-19 pandemic, just over a third of parents reported that they would have liked more support 'very much'.

In terms of the COVID-19 pandemic, we found that a large proportion of parents experienced disruptions to their child's healthcare. Cancellations and postponements were most frequently reported by parents in the UK and Poland. For example, a third of parents in these countries reported cancelled or postponed surgeries, compared with only 8% in Germany. Specialist doctors and GPs had the lowest satisfaction with support ratings during the pandemic, which again were particularly poor in Poland, the UK, and Italy. In contrast, Poland had the highest satisfaction ratings for support from patient organisations and peers.

Strengths of the survey

- We included a broad range of experiences, as we included parents of children with different congenital anomalies living in several European countries.
- A large total number of parents were surveyed.

Limitations of the survey

- The views of the parents who completed the survey may not be representative of all parents of children with CAs, particularly as we used social media to advertise the study (and not all parents will access information about their child's health condition this way).
- We advertised the study in the same way across countries. However, some countries were more successful in recruiting parents than others as they were supported by more organisations to reach parents. It is possible that these differences may have affected our findings across countries.

5. Conclusion

Our findings indicate that parents obtain information about their child's health condition from a range of medical and informal sources. Medical specialists were the most frequently used source of information, and were also rated the most highly for helpfulness and trustworthiness. Informal sources of information appeared to be of value to parents however they were not deemed as trustworthy. With trust in these information sources lacking, it is important that healthcare professionals actively signpost parents to reliable sources of information, such as clear medical websites. Overall satisfaction with information was somewhat low and indicates a potential information gap. Around the time of diagnosis there was a high level of unmet need in terms of support from professionals. It will be important to explore the reasons why this support was lacking. Findings relating to the COVID-19 pandemic highlight disruptions to the delivery of care across Europe, particularly in the UK and Poland, which raises questions about the ability of the healthcare systems within these countries to meet the needs of children with congenital anomalies and their families.

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7. Appendix

Table 1 Parent characteristics overall and by country.

Characteristic	All	UK	Poland	Germany	Croatia	Italy	Belgium/ Netherlands	Other EU†
Number of survey respondents	986	120	476	97	68	59	74	92
Age								
≤30	162 (17%)	18 (15%)	93 (20%)	13 (13%)	8 (12%)	4 (7%)	15 (20%)	11 (12%)
31-40	516 (53%)	53 (45%)	264 (56%)	51 (53%)	37 (55%)	27 (46%)	35 (47%)	49 (53%)
>40	301 (31%)	47 (40%)	115 (24%)	33 (34%)	22 (33%)	28 (47%)	24 (32%)	34 (35%)
Relation to child								
Mother	911 (92%)	116 (97%)	449 (94%)	81 (84%)	63 (93%)	52 (88%)	64 (86%)	86 (95%)
Father	65 (7%)	2 (2%)	24 (5%)	13 (13%)	5 (7%)	6 (10%)	10 (14%)	5 (5%)
Other‡	8 (1%)	1 (1%)	3 (1%)	3 (3%)	-	1 (2%)	-	-
Employment								
Employed	586 (60%)	81 (68%)	223 (47%)	61 (62%)	54 (79%)	44 (75%)	61 (82%)	62 (69%)
Homemaker/carer	301 (31%)	36 (30%)	198 (42%)	27 (29%)	7 (10%)	11 (19%)	8 (11%)	14 (16%)
Other*	94 (9%)	3 (3%)	52 (11%)	9 (9%)	7 (10%)	4 (7%)	5 (7%)	14 (16%)
Education								
School ≤18 years/technical training	390 (40%)	44 (37%)	163 (35%)	61 (67%)	19 (28%)	30 (52%)	44 (60%)	29 (32%)
University	482 (49%)	50 (42%)	257 (53%)	27 (29%)	45 (66%)	19 (33%)	29 (39%)	55 (60%)
Post-graduate	106 (11%)	25 (21%)	56 (11%)	3 (3%)	4 (6%)	9 (16%)	1 (1%)	8 (9%)
Migrant status								
>10 years/from birth	924 (94%)	111 (93%)	467 (98%)	86 (88%)	64 (94%)	50 (86%)	71 (96%)	75 (81%)
6-10 years	30 (3%)	5 (4%)	5 (1%)	6 (7%)	2 (3%)	4 (7%)	1 (1%)	7 (8%)
1-5 years	28 (3%)	4 (3%)	2 (0.4%)	5 (5%)	2 (3%)	4 (7%)	2 (3%)	9 (10%)
<1 year	2 (0.2%)	-	1 (0.2%)	-	-	-	-	1 (1%)

†Other European countries: Denmark (n=39), Portugal (n=23), Spain (n=16), Ireland (n=5), Bulgaria (n=2), Albania (n=1), Cyprus (n=1), Lithuania (n=1), Norway (n=1), Romania (n=1), Sweden (n=1), Ukraine (n=1).

‡Other family member (n=3), legal guardian related to the child (n=2), legal guardian unrelated to the child (n=3).

*Unemployed (n=56), long-term sick/disabled (n=17), on furlough (n=12), student (n=8), retired (n=1)

Table 2 Percentage of parents reporting that information accessed/received from each of the following sources was 'very helpful', by country.

Country	Specialist doctors/nurses n†=918	GPs n†=767	Leaflets n†=638	Research books/articles n†=756	Patient organisations n†=727)	Support groups n†=747	Social media n†=816	Internet searches n†=919
Poland	46%	18%	18%	50%	65%	73%	68%	41%
UK	68%	18%	27%	31%	54%	55%	49%	32%
Croatia	65%	37%	29%	43%	53%	64%	53%	34%
Italy	74%	36%	10%	36%	82%	48%	44%	30%
Germany	75%	37%	38%	67%	60%	61%	47%	39%
Belgium/Netherlands	77%	20%	17%	27%	33%	23%	21%	21%
Other EU	59%	19%	29%	43%	58%	60%	44%	42%
Total	58%	24%	22%	44%	60%	63%	56%	38%

†Total number of parents who answered the question, excluding those who selected 'not applicable'. Missing data: specialist doctor/nurse (n=10), GP (n=9), leaflets (n=15), research books/articles (n=18), patient organisations (n=24), support groups (n=18), social media (n=17), internet searches (n=13).

GP = general practitioner

Table 3 Percentage of parents reporting that they found the information received or accessed from the following sources 'very trustworthy', by country.

Country	Specialist doctors/nurses n†=911	GPs n†=740	Leaflets n†=639	Research books/articles n†=740	Patient organisations n†=725	Support groups n†=761	Social media n†=811	Internet searches n†=888
Poland	46%	20%	22%	45%	51%	55%	42%	23%
UK	75%	33%	47%	30%	35%	35%	20%	15%
Croatia	79%	45%	38%	59%	46%	36%	25%	18%
Italy	73%	62%	28%	26%	72%	35%	34%	20%
Germany	83%	70%	73%	70%	56%	55%	42%	22%
Belgium/Netherlands	80%	61%	45%	46%	26%	19%	13%	8%
Other EU	71%	35%	47%	51%	50%	45%	28%	25%
Total	62%	37%	37%	45%	49%	47%	34%	20%

†Total number of parents who answered the question, excluding those who selected 'not applicable'. Missing data: specialist doctor/nurse (n=13), GP (n=11), leaflets (n=21), research books/articles (n=19), patient organisations (n=21), support groups (n=15), social media (n=35), internet searches (n=14). GP = general practitioner

Table 4 Percentage of parents reporting that they would like more information about each topic, in the total group and by each congenital anomaly group

Topic	Total n=986	Cleft Lip n=230	Spina bifida n=112	Congenital heart defect n=327	Down syndrome n=262	DS + CHD n=55
Intellectual development	51%	30%	37%	48%	74%	75%
Treatment options	42%	43%	64%	43%	30%	40%
Physical development	40%	22%	52%	50%	40%	33%
Support from school	35%	27%	39%	24%	52%	48%
Positive information about child's full potential	34%	21%	34%	34%	46%	38%
Diet and feeding	33%	22%	20%	31%	50%	44%
Specialist medical centres	32%	33%	46%	27%	33%	25%
Quality of life	30%	14%	33%	43%	28%	27%
Financial support	24%	28%	34%	16%	27%	29%
Exercise	19%	16%	28%	23%	15%	13%
How to meet other parents	17%	23%	18%	17%	13%	11%
Sleep	11%	7%	3%	9%	18%	18%
Patient organisations/support groups	11%	15%	10%	12%	8%	15%
No more information required	8%	17%	4%	7%	3%	4%

Percentages highlighted in **bold** represent the highest three scoring topics for each column.

DS – Down syndrome; CHD – congenital heart defect.

Table 5 Percentage of parents reporting ‘cancelled or postponed’ routine appointments, planned tests or procedures, and planned surgeries during the pandemic, by country.

Country	Routine appointments N†=920	Planned tests or procedures N†=803	Planned surgeries (N†=609)
UK	86%	67%	33%
Poland	79%	65%	35%
Germany	31%	18%	8%
Croatia	44%	36%	13%
Italy	70%	54%	11%
Belgium/Netherlands	39%	23%	16%
Other EU	57%	43%	12%
Total	67%	53%	25%

† Total number of parents responding to the question excluding ‘not applicable’ responses (e.g. where the person had no planned surgeries during the survey time period). Missing data: routine appointments (n=9), planned tests or procedures (n=8), planned surgeries (n=5).

Table 6 Percentage of parents reporting that they had appointments re-scheduled as virtual, virtual appointments rated as ‘poor’, and problems accessing medication during the pandemic, by country.

Country	Appointments re-scheduled as virtual N†=891	Virtual appointments rated as ‘poor’ N†=552	Problems accessing medication N†=713
UK	87%	21%	42%
Poland	71%	37%	34%
Germany	25%	0%	7%
Croatia	46%	17%	4%
Italy	37%	27%	14%
Belgium/Netherlands	34%	5%	19%
Other EU	12%	22%	8%
Total	61%	29%	26%

†Total number of parents answering the question excluding ‘not applicable’ responses. Missing data: appointments re-scheduled as virtual (n=8), virtual appointments rated as ‘poor’ (n=11), problems accessing medication (n=8).

Table 7 Percentage of parents reporting that they were 'very satisfied' with the support they received from each source during the pandemic, by country.

Country	GP N†=775	Specialist doctor/nurse N†=792	Partner N†=868	Friends/family N†=883	Parents of other children N†=637	Patient organisations N†=510	Schools N†=369
UK	25%	39%	79%	49%	51%	38%	47%
Poland	26%	34%	69%	61%	66%	56%	27%
Germany	85%	84%	89%	73%	60%	59%	39%
Croatia	41%	46%	80%	64%	64%	36%	19%
Italy	44%	31%	71%	47%	44%	33%	42%
Belgium/ Netherlands	57%	59%	66%	49%	33%	14%	36%
Other EU	45%	45%	70%	52%	56%	38%	33%
Total	37%	42%	72%	58%	60%	46%	34%

†Total number of parents answering the questions, excluding 'not applicable' responses. Missing data: GP (n=10), specialist doctor/nurse (n=16), partner (n=11), friends/family (n=14), parents of children with same condition (n=17), patient organisations (n=18), schools (n=35).
GP = general practitioner