

The State of the Nation

September 2023

Access Social Care: Helplines Data Collaboration Group



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Executive summary

Every day, millions of older and disabled people are denied the social care they need. Most local authorities cannot meet the growing demand for care. Adult Social Care Directors have had to identify an increased level of savings from their adult social care budgets for 2023/24: £806m, up from £597m in 2022/23¹. Three quarters of Directors across English Councils say they aren't confident about being able to fully offer the minimum social care support required by law in their communities.² This affects all of us because we will all need social care at some point. We all have a right to hold public bodies to account, but millions of us cannot afford lawyers so rely on legal aid. The 77% reduction in community care legal aid cases since 2010 means we have nowhere to turn.

Without access to justice, our rights do not exist. The rule of law is broken.

The Association of Directors of Adult Social Services reported in Spring 2023 that 434,243 people are still waiting in some shape or form for an assessment, a review of their care plan, or revised care and support. There has been a 13% increase in those waiting 12 months or longer in the past year. Some of these people will inevitably deteriorate whilst waiting, either becoming ill and needing hospital or relying on unpaid carers³. More councils overspent on their adult social care budget last year and there has been an increase in those relying on reserves to fund these pressures. Nearly two-thirds (63%) of councils in England overspent on their adult social care budgets in 2022/23, with 72% of those councils using one-off reserves to fund the gap⁴. This is unsustainable.

It is widely acknowledged that the resources available for social care have not risen at the same rate as demand. And yet, data gathered on this critical issue by local authorities and central government about unmet need for social care remains inadequate. If we are to fully understand the level of both rising demand and existing service provision, social care data must improve. Access Social Care leads this data collaboration project in partnership with helplines at Royal Mencap Society, Age UK, Carers UK, Independent Age, RNIB, Scope, Citizens Advice and Ealing Advice Consortium. We welcomed Citizens Advice and Scope this year. We combine reflections from our work supporting people with care and support needs with findings from this project to describe emerging themes.

Our third State of the Nation report explores the increasing need that people have for social care advice, highlights the external factors which may have driven some of this increased need, and details the complexities of some of the issues that those in need are now facing. This report draws together over 300,000 separate data points through a bespoke processing pipeline built and maintained at Access Social Care and detailed at Annex B, C & D. We have matched 1,158 separate organisational data categories to a set of harmonised group categories ('universal themes' detailed at Annex A). These universal themes match similar group member queries into one category (further information on process at Annex B-D), allowing us to derive greater collective insight across the sector. We categorise member data into group types: 'carers', 'older people', 'physical and sensory disability', 'learning disability' and 'general public'. Due

¹ [adass-spring-survey-2023-key-messages_conclusions_recommendations-1.pdf](#) page 3

² [adass-spring-survey-2023-key-messages_conclusions_recommendations-1.pdf](#)

³ [adass-spring-survey-2023-key-messages_conclusions_recommendations-1.pdf](#) page 3-4

⁴ page 3 [adass-spring-survey-2023-key-messages_conclusions_recommendations-1.pdf](#)

to the specific availability of 'physical and sensory disability' data, 'physical and sensory disability' is included in the 'Year in Review' analysis only, looking back at common social care themes in 2022-23. Whilst some areas of advice provision have stabilised in volume, this is concerningly at a higher level than pre-pandemic volume in several areas. People continue to struggle in accessing care and support.

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With special thanks to Owen Bowden, Insight and Analytics Lead at Royal Mencap Society who has contributed to this project.

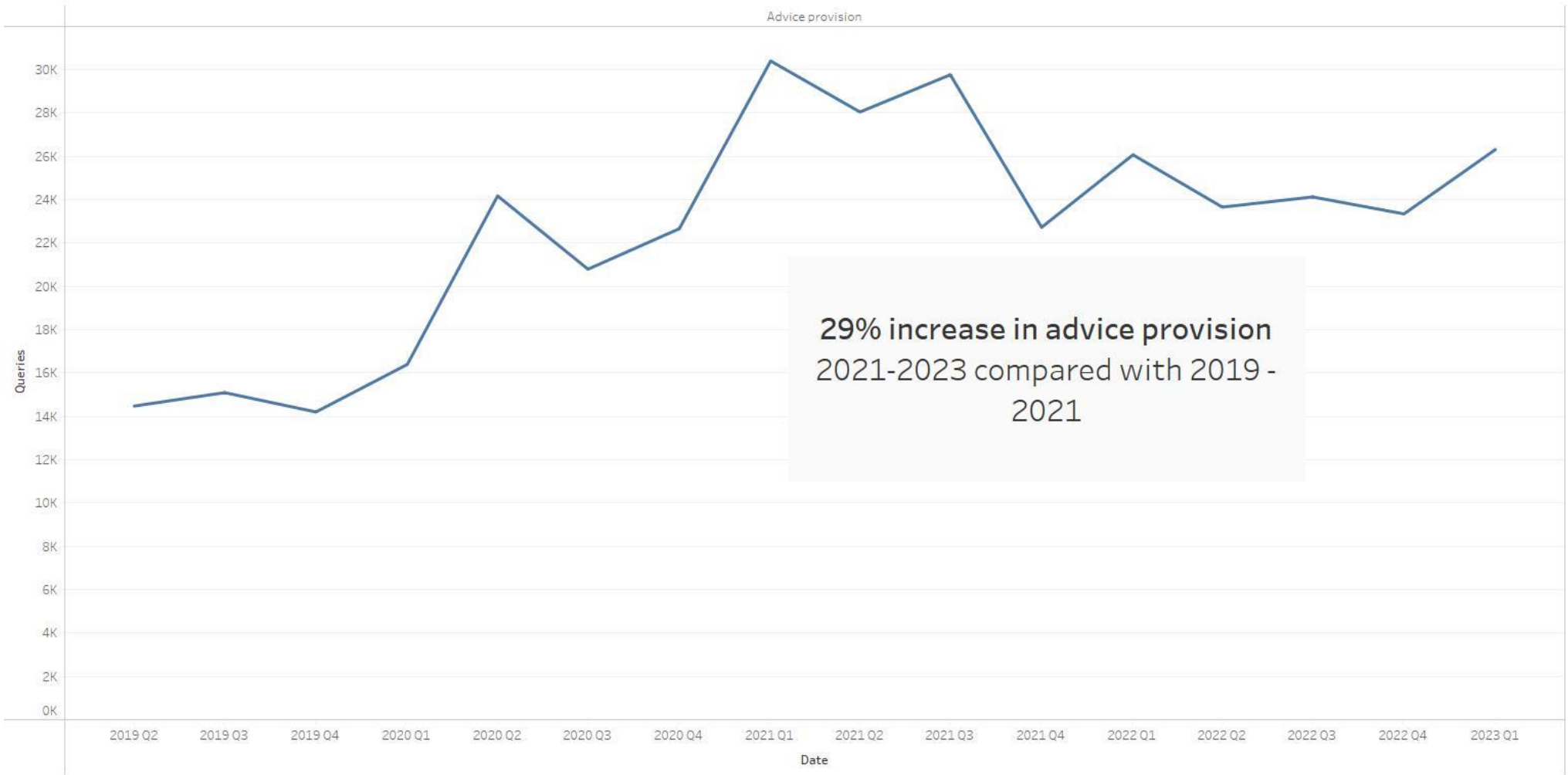
Key findings

Our members observed the following between 2021 – 2023 when compared with data from 2019 – 2021 (please note that due to the availability of data, physical and sensory disability data is not included for the purposes of our 2019 – 2023 analysis):

- **29%** increase in overall volume of individual **social care advice queries** to all helplines
- **95%** increase in enquiries that were identified as needing **specialist legal advice**
- **123%** increase in the number of enquiries about social care **needs assessments**
- **100%** increase in the number of enquiries about accessing **social care statutory advocacy**
- **80%** increase in the number of enquiries relating to **being a carer**
- **48%** increase in the number of enquiries from **people seeking general information** about social care
- **375%** increase in the number of enquiries about **mental capacity**



Advice provision
2019-2023



Our members saw a 29% increase in overall contact on social care queries to their helplines in the last two years compared to the previous two years. This uplift reflects the large spike of queries primarily about assessment, care plan and carer queries from 2021 onwards.

434,243 people are still waiting for assessments, care and support, direct payments or reviews⁵ – some of the increase in advice provision relates to peoples' increasing or unmet need whilst they are awaiting this support. Of this figure, 224,978 people are awaiting assessments⁶. At the same time, as we detail further below, local authorities are having to make significant decisions about cost efficiencies including across adult social care, resulting in some receiving a decrease in care and support. This is compounded by sector wide staff shortages.

Several of our participating helpline organisations ('members') subsequently experienced operational changes in 2022, including changes to web servers and case management systems. Some members experienced higher than usual staff sickness in 2022. Some of the spikes in contacts throughout 2021 are understood by many of our members to be related to people with care and support needs emerging from the arrangements of the initial phases of the COVID-19 pandemic and needing longer term care and support planning; that is to say, the emergence of post-Covid long term planning.

We expect some seasonal variations between around October/November and January/February of each year, as differing and competing areas of priority for people change across the year. For example, debt and housing advice often increases in December and January of each year for many members into the first calendar quarters as these can be the areas of highest priority for people in this season. Our group will be investigating the possibility of gathering new data, in addition to social care codes, such as housing and debt advice in 2023/24 to further investigate. So, whilst we observe a trend of seasonal decreases in some areas of social care advice, most of our members report that alternative advice areas spike in this time.

When we analyse the trends in overall volume to each member on social care advice queries, we observe that the diversity of queries varies significantly by partner. Queries recorded per member organisation relate to **social care queries who have contact with a helpline advisor only** and do not reflect overall helpline volumes.

Some of our members see an increase in social care advice queries into 2023, others see a stabilisation, and some see a reduction. Some of the reduction for many members relates to a series of issues, including but not limited to:

- A stabilisation of volume following the second wave of COVID-19 which had seen record increases
- Seasonal variances
- Operational reasons including changes to case management systems, changes to web servers and staff sickness – all preventing helpline advisors from answering as many calls.

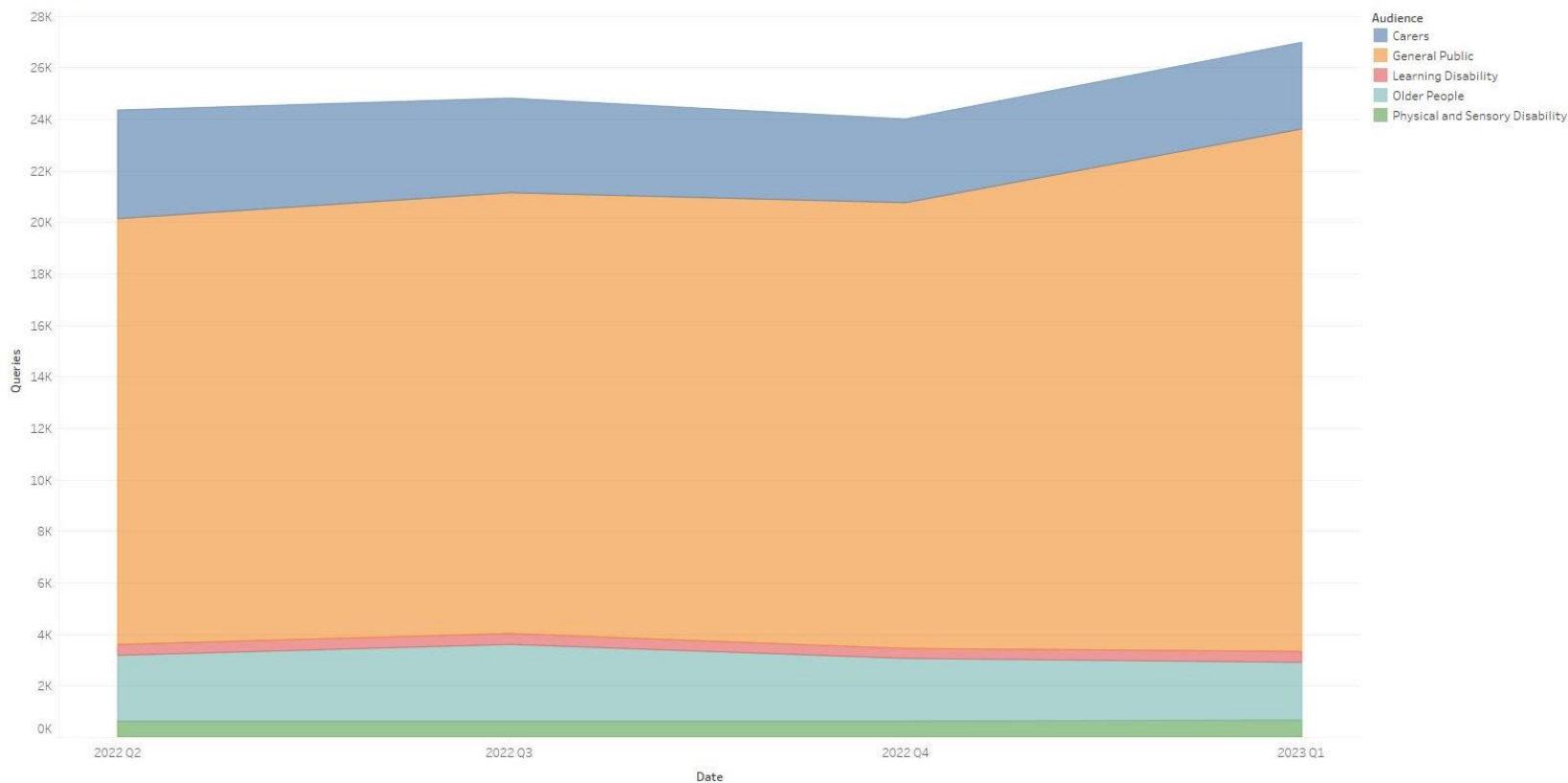
⁵ [adass-spring-survey-2023-final-web-version.pdf](#) section 8

⁶ [adass-spring-survey-2023-final-web-version.pdf](#) section 8

Audiences

Data is collected for all audiences apart from 'physical and sensory disability' from 2019 onwards. 'Physical and sensory disability' data is available from mid-2021 onwards. To give a view across all audiences as to volumes we have therefore focused the audience graphs below on fiscal year 2022-2023. Our 'General public' audience includes social care queries which do not provide detail about the type of need, for example learning disability, so will include a range of different and wide-ranging social care needs.

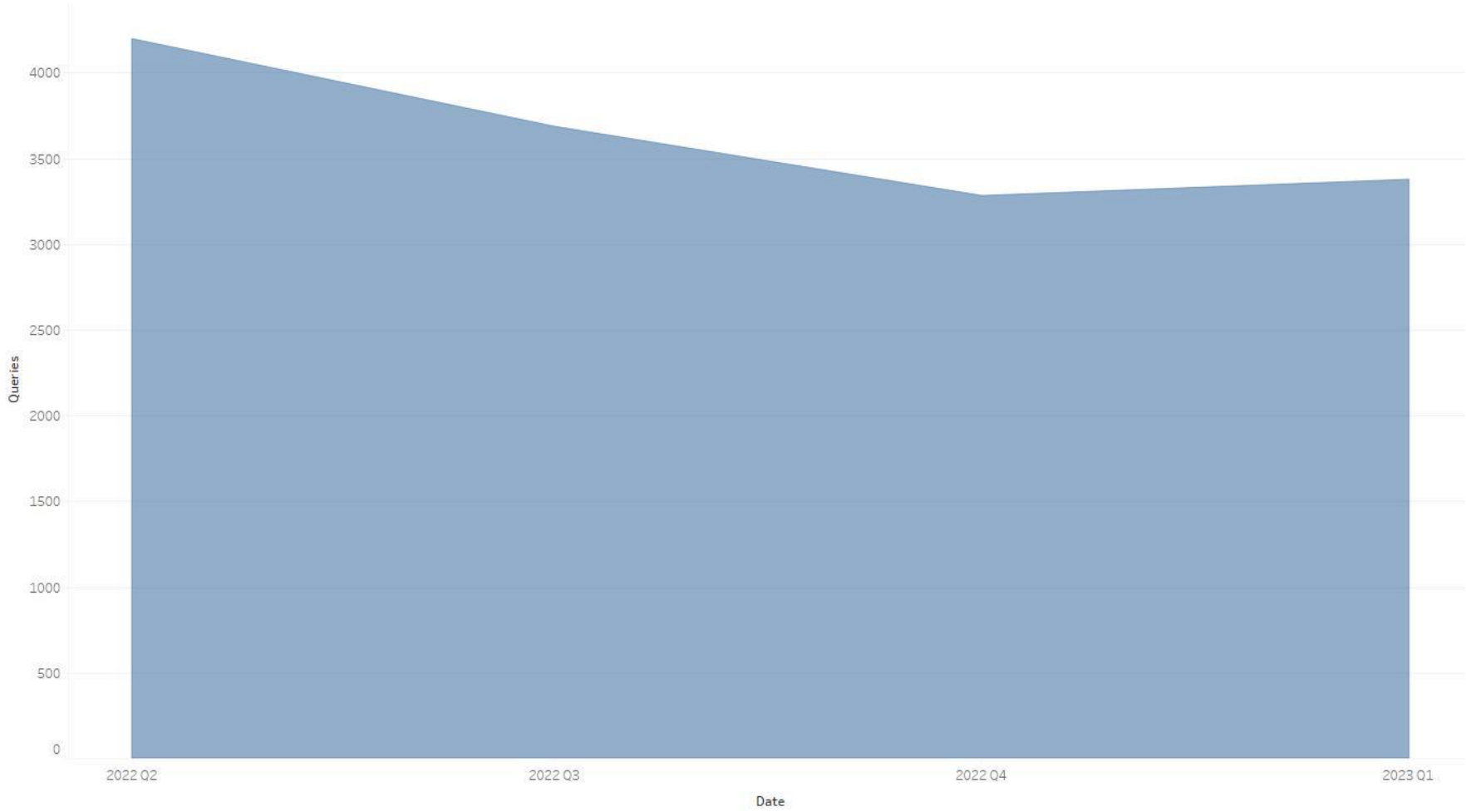
Audiences
2022-2023



Most audiences see some increases in volume from January 2023. These rises either stabilise or continue to rise into the first quarter of 2023, with our carers and general public audiences seeing continued increases into 2023.

Audience: Carers

Audience
2022-2023



Audience: Carers

We see an expected seasonal decrease in queries at the end of 2022, which we expect based on previous years to either stabilise or increase further into Q2 of 2023. But it is important to note that Carers UK saw the highest spike of queries throughout the COVID-19 pandemic and figures remain significantly elevated compared to pre-pandemic.

Our members report that whilst social care queries decrease during this period, other areas such as debt and housing significantly increase. Carers UK state in their response to the ADASS Spring Survey⁷:

“Given the poorly funded and overstretched state of social care in England, it is no longer surprising that 91% of directors said that unpaid carers are coming forward with increased levels of need – but this stark statistic shows there is so much work that urgently needs to be done to support unpaid carers with their caring roles. Lack of support services and care workers mean unpaid carers are having to provide more care at a greater cost to their health and wellbeing, and as more people reach crisis point, ADASS believes there will be a rise in carers forced to reduce hours or leave work. This will cost health and social care, the Government and employers more in the longer run.

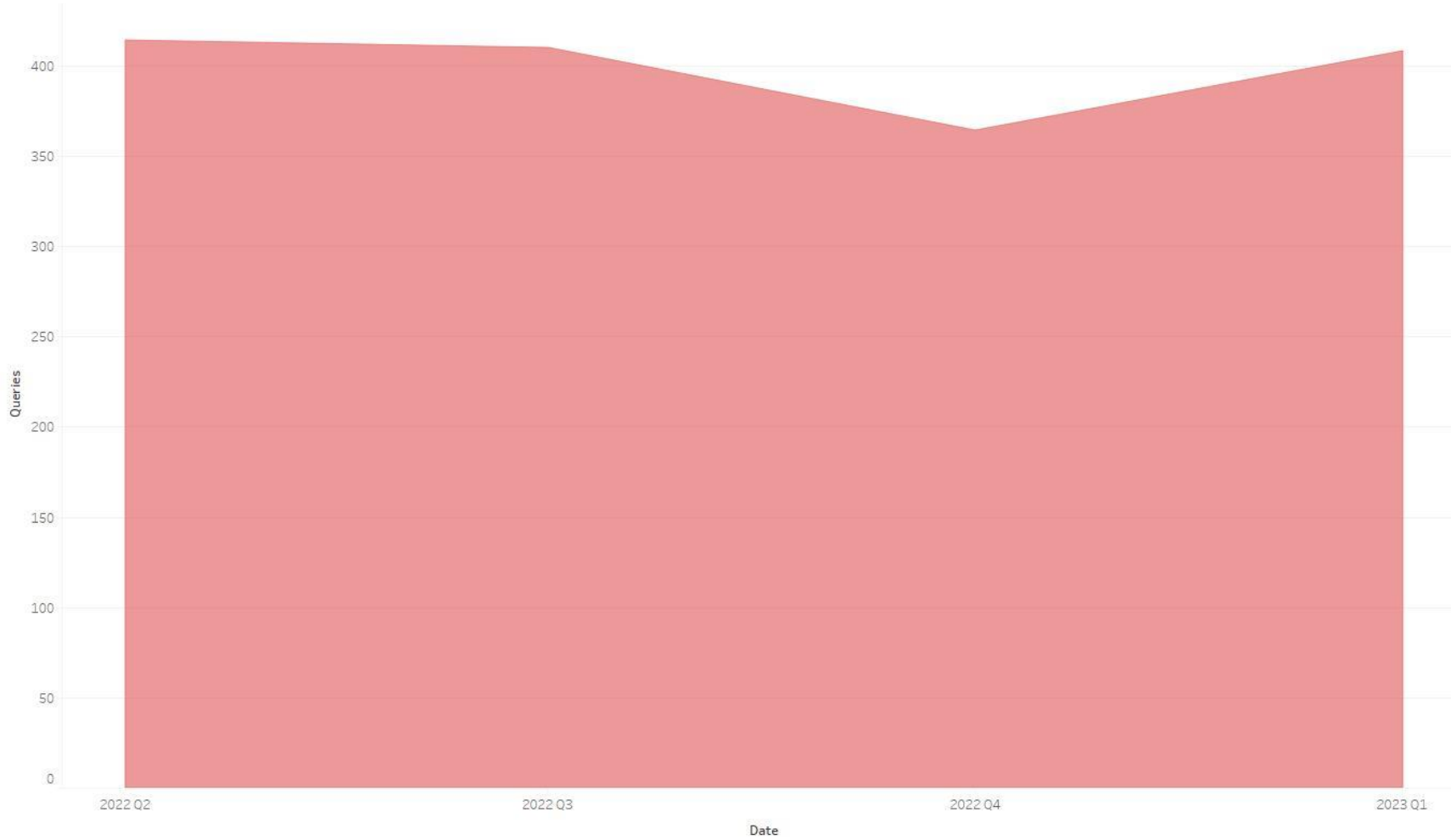
“The survey found that most councils say they’re not confident they can offer the minimum social care support in their communities required by law: this should be major cause for concern. These are services that families desperately need to maintain their quality of life and the Government needs to show it is taking social care and them seriously.”



⁷ <https://www.carersuk.org/press-releases/carers-uk-responds-to-2023-adass-spring-survey/>

Audience: Learning disability

Audience: Learning Disability
2022-2023



Audience: Learning disability

Social care contacts from those with, or caring for someone with, a learning disability increase as is seasonally expected in the first quarter of 2023. On 16 March, the Government released a Spring Statement (also known as the Spring Budget) updating the public about its progress towards its financial goals.

Jackie O'Sullivan, Executive Director of Communication, Advocacy and Activism at Mencap responded to the Spring Statement:

"Today's budget included absolutely nothing to tackle the dire state of social care and the NHS. Instead the Chancellor prioritised crumbling roads over the crumbling social care and health system.

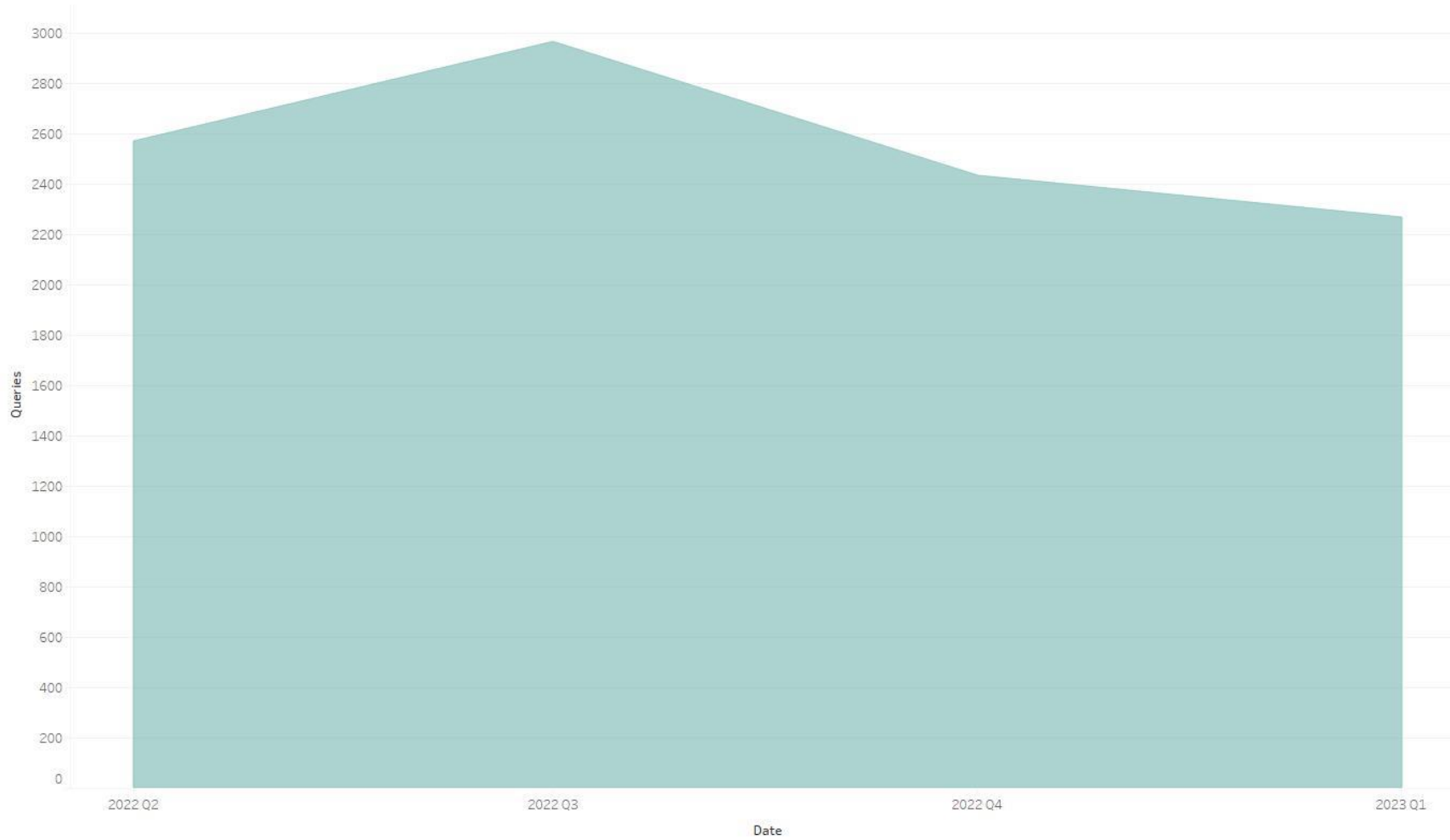
The extended energy support announced in today's budget is welcome, but the Government should commit to long-term targeted support and introduce a discounted social energy tariff.

The Disability White Paper promises some positive changes for people with a learning disability, like the removal of the Work Capability Assessment, but as always the devil is in the detail. The government continues to focus on threats and financial sanctions, rather than addressing inadequate benefit rates and investing in supporting people into work. These priorities reflect a lack of understanding of the experience of people with a learning disability."



Audience: Older people

Audience: older people
2022-2023



Audience: Older people

We see an expected seasonal decrease in queries at the end of 2022, which we expect based on previous years to either stabilise or increase further into Q2 of 2023. Our members report that whilst social care queries decrease during this period, other areas such as debt and housing significantly increase. Age UK have produced a ['State of the Older Nation' report](#) this year that sets out analysis of our older population's health and care needs, and how well they are being met. The report notes:

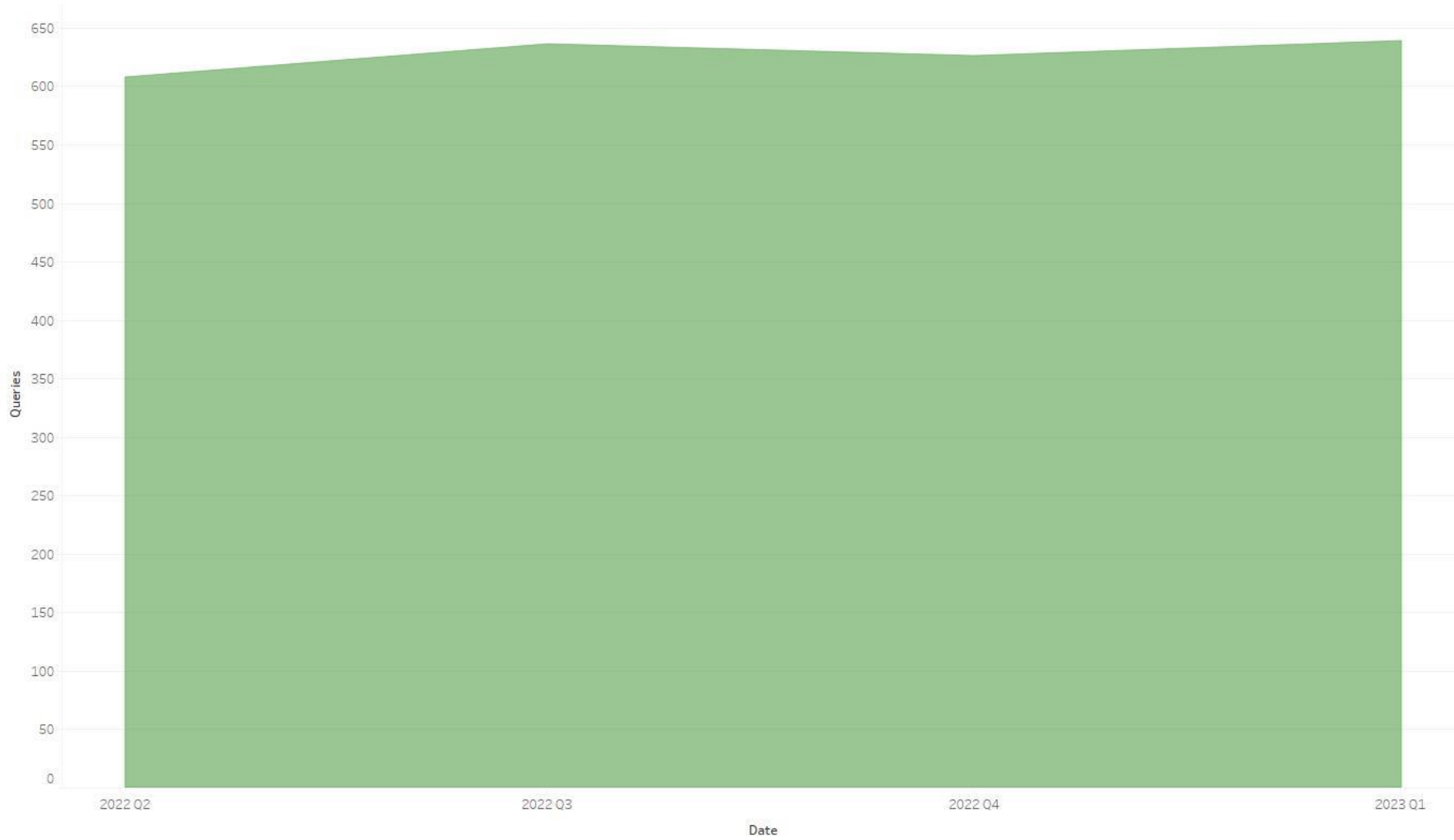
We are struck by three key messages:

- 1) Covid has cast a long shadow over older people's health and social care – one which continues to this day. Too many people still have poor mental or physical health which can be attributed to the Covid period. It's not surprising that hospitals and care services are under pressure because need has unquestionably risen.
- 2) There are particular groups of older people, such as those from some ethnic minorities or living in deprived communities, whose experience is even worse than the rest of the population.
- 3) The forward trends set out cannot be ignored – it is simply a matter of time before our health and care system buckles under the needs of an increasingly older population



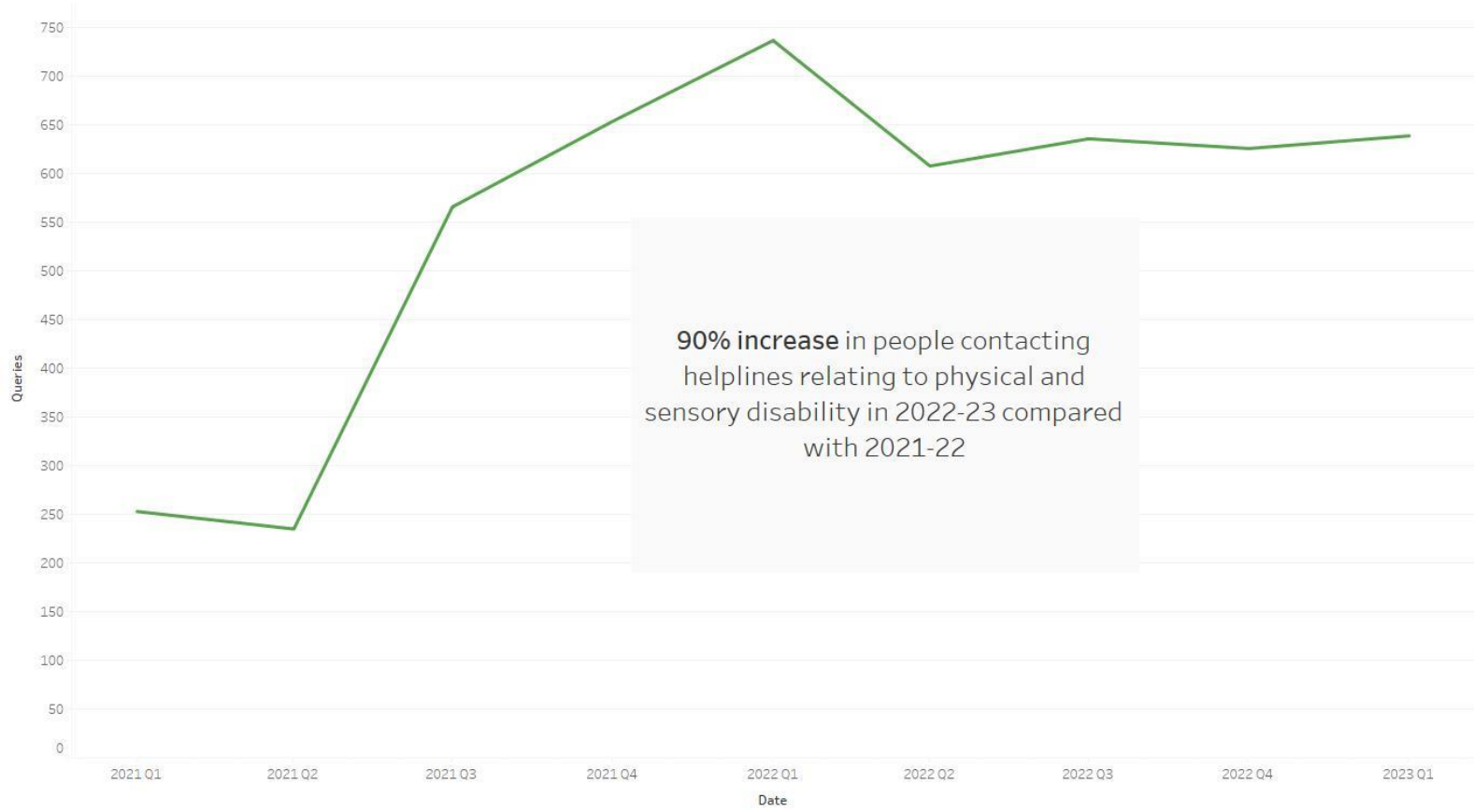
Audience: Physical and sensory disability

Audience: physical and sensory disability
2022-2023



Due to the availability of data, physical and sensory disability cannot be included in our 2019-2023 analysis. We can however observe over a two year period:

Physical and sensory disability
2021-2023



We observe a 90% increase in contacts relating to physical and sensory disability over a two-year period. Some of this increase is attributable to one of our group members case management systems undergoing improvement which allowed greater data capture.

RNIB state:

“Blind and partially sighted people and those losing their sight continue to be failed by our social care services. People still struggle to locate the source of help, have their needs inadequately assessed and fail to get the support and equipment they require.

We want to see a care system that is targeted and funded to meet blind and partially sighted people’s needs⁸.”

James Taylor, Scope states:

“Disabled people are caught in the middle of the current cost of living storm. Inflation is predicted to hit 10 per cent later in the year, as energy bills rocket, and food prices shoot up. But this is on top of the extra costs that many disabled people already faced.

Energy for powering essential equipment such as hoists, beds, breathing equipment, powered chairs and monitors was already expensive. We’ve previously shown that extra costs faced by disabled people add up to £583 a month on average.

These are not optional extras that can be cut back. This is vital, often lifesaving, equipment. Some disabled people and their families are simply past the point of being able to cut back anymore and cannot afford to get by. Some, face the terrifying reality of not being able to afford the basics. Facing the stark choice daily of heating or eating.

Scope storyteller Jignesh Vaidya is paralysed from the waist down and gets cold easily. He holds down two jobs, but already has been forced to cut all expenditure for him and his young family right back to the bone. It’s likely this will get worse before it gets better.

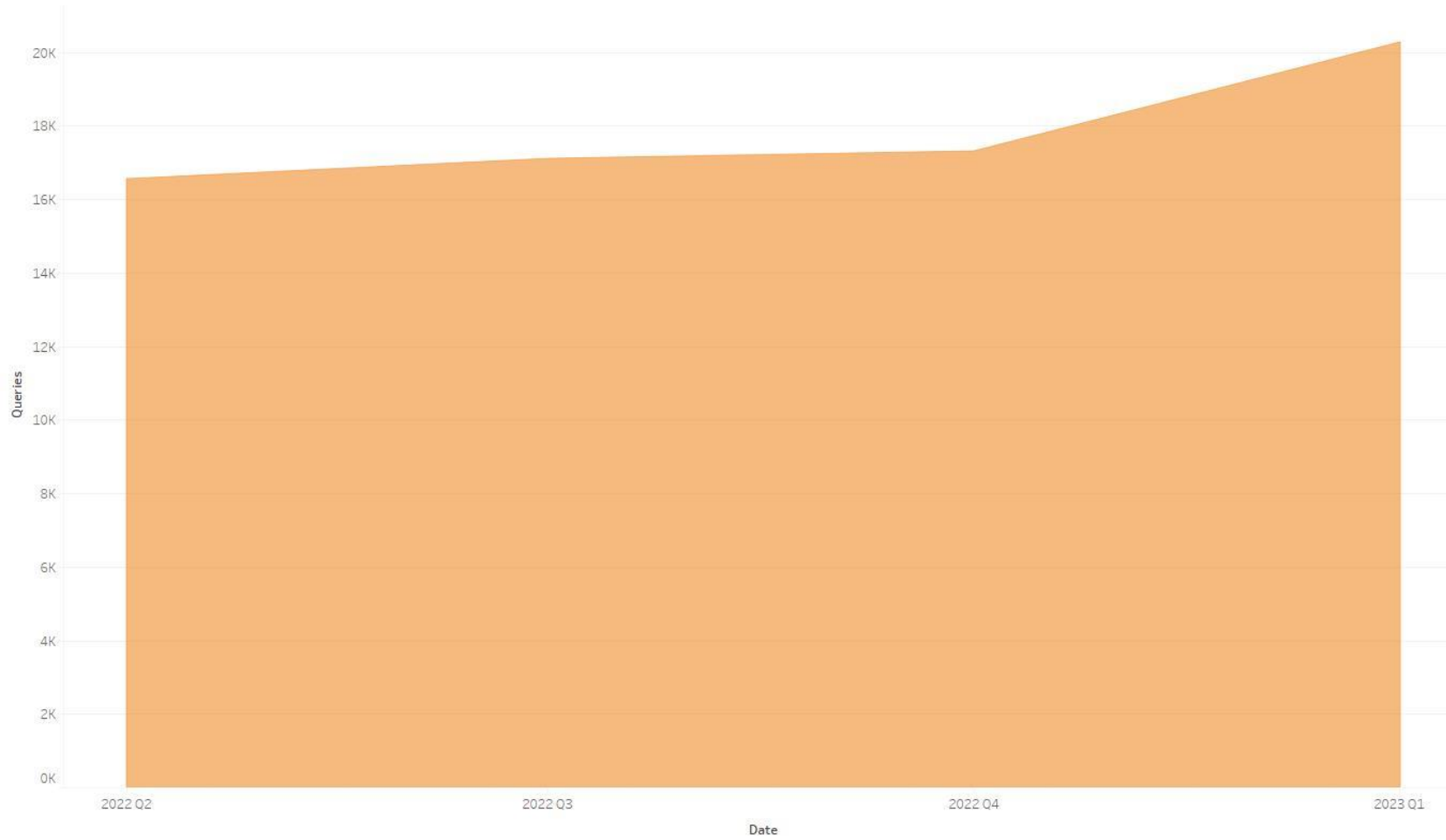
We’ve seen a huge rise in calls from disabled people to our helpline and our [Disability Energy Support service](#) – concerned about bills and how they’ll make ends meet.⁹

⁸ [Policy Statements | RNIB](#)

⁹ [Why disabled people are at the centre of the cost-of-living crisis | Disability charity Scope UK](#)

Audience: General public

Audience: general public
2022-2023



Audience: General public

We observe a 17% increase in queries from our general public audience in calendar quarter one of 2021 compared with the previous quarter. This is rising in line with expected seasonal increases in addition to record numbers of people seeking advice.

Dame Clare Moriarty, Chief Executive of Citizens Advice, said:¹⁰

“The cost-of-living crisis is far from over. The fact we’ve experienced our bleakest ever start of the year shows the government cannot afford to turn their gaze away from the issues people are facing.

“Millions of people are doing everything they can but it’s still not enough. Too many people are living on empty, simply unable to pay their bills and put food on the table. And while staff and volunteers in local offices work tirelessly every day to help people, there’s only so much we can do.

“We can see government support helps, but more is needed in the future for struggling households. For many, life is getting worse, not better.”

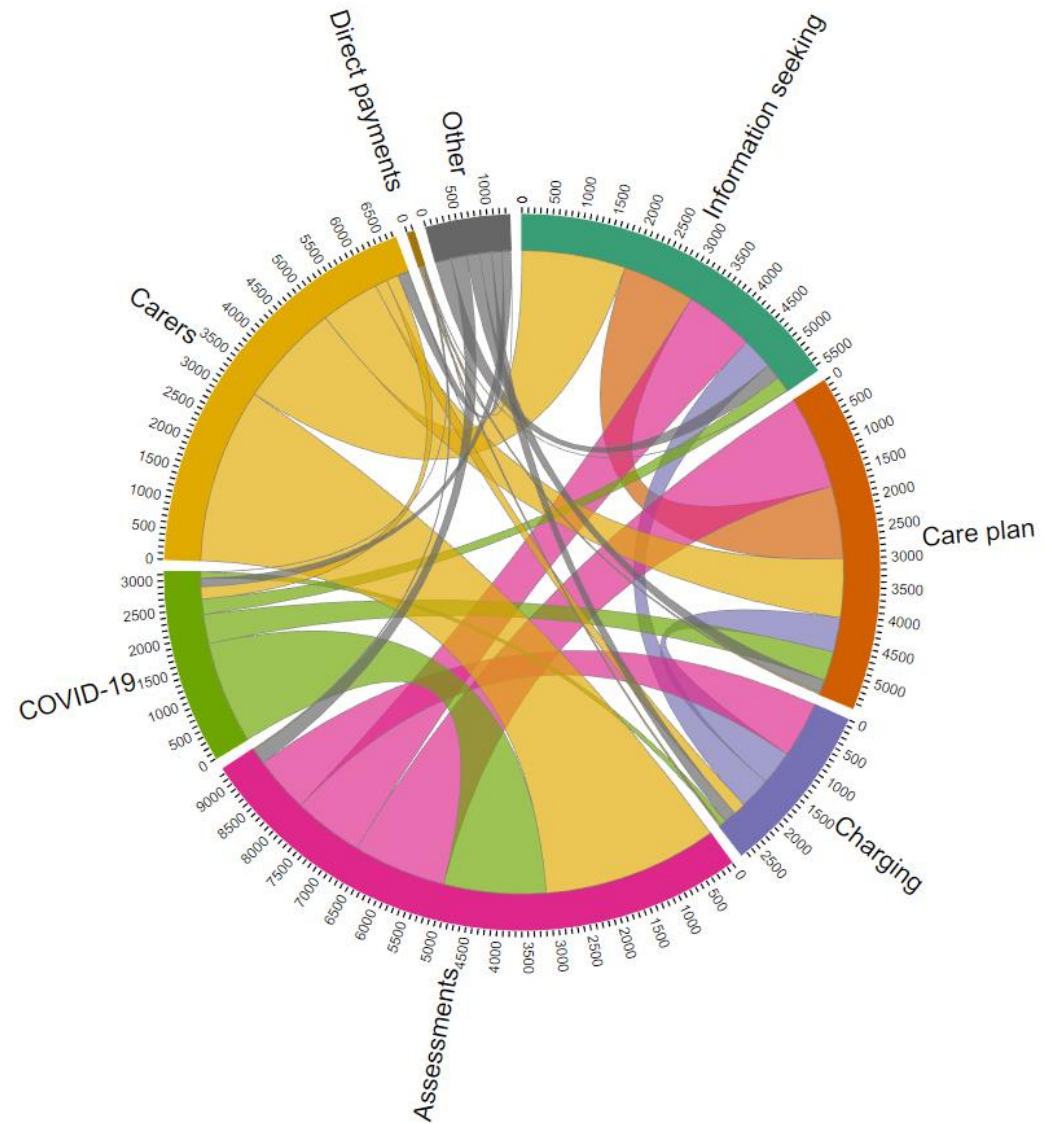


¹⁰ [“Our bleakest-ever start to the year” - number of people helped by Citizens Advice at record high - Citizens Advice](#)

Thematic analysis: 2019 – 2023

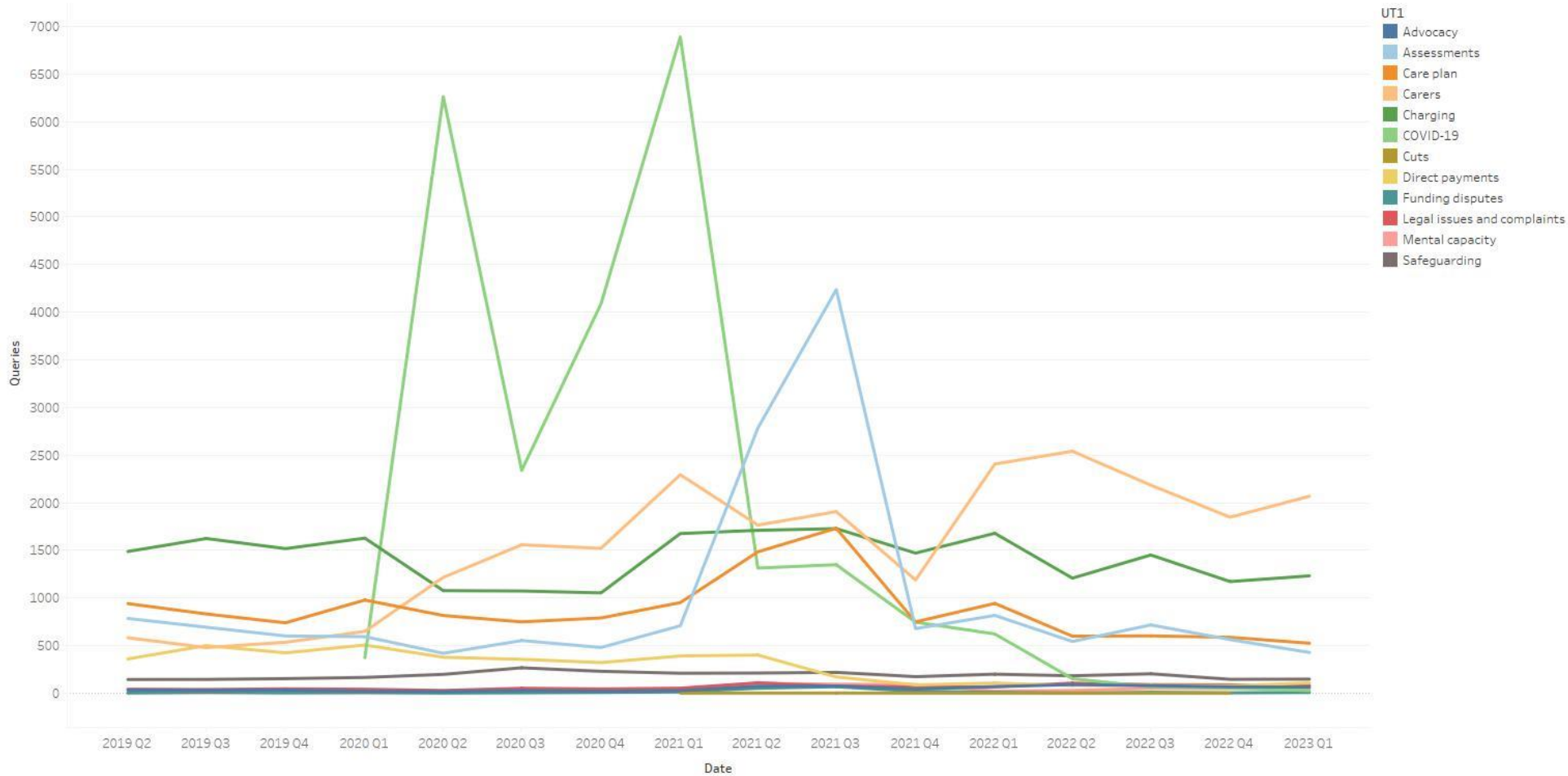
While the majority of this report discusses individual themes, it's important to note that most people's needs are complex and varied, and thus when advice seekers call a member helpline, a single call will frequently fall under several categories. This chart demonstrates the degree to which incoming queries map to several universal themes.

A small caveat to the chart: not all partners provided disaggregated information, and thus this picture might not be representative of all our members' experiences, but it does serve to provide an overview. We can readily see that Assessments queries are highly correlated with Carers queries, and that the majority of COVID concerns were also related to Assessments more than anything else. Care Plan concerns seem to be connected to the other universal themes fairly evenly.



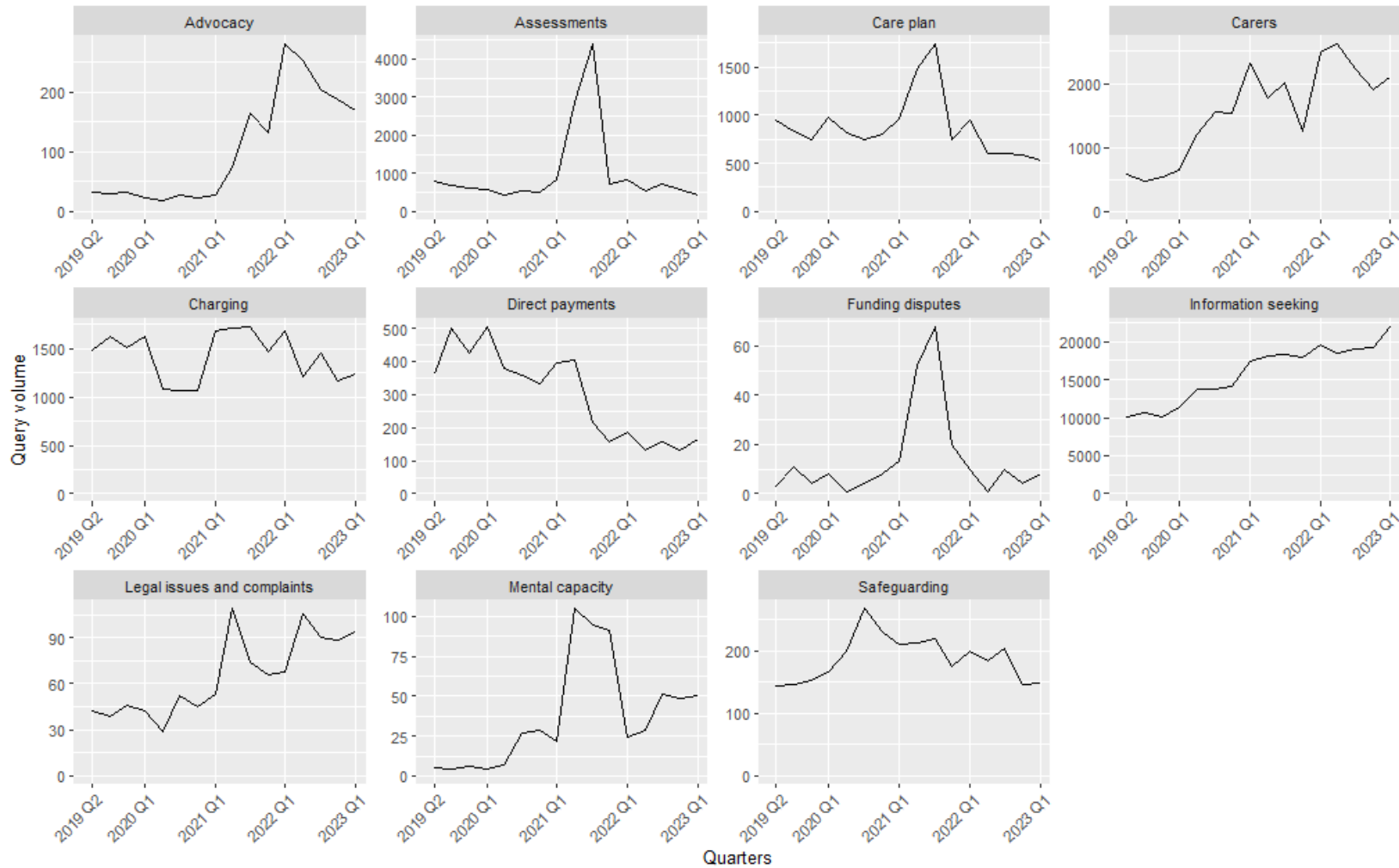
We set out below our analysis of the group's carers universal theme. Queries rose in line with the first and second wave of COVID-19, and although they are beginning to stabilise, we observe that in several areas this appears to be at a significantly higher volume than pre-pandemic, such as with mental capacity queries. The "Information Seeking" area has been suppressed from this chart to facilitate visualization, but is set out in further detail below.

Universal themes
2019 - 2023



Due to the large number of categories, we present the same chart disaggregated by themes, each in its own facet. Note: the scale is applicable to each facet only, as displayed in each chart's axes.

Overall inquiries by Thematic area



Most themes include common seasonal variances, typically lower social care queries between October-November and January-February. Alternative areas of advice such as debt and housing issues commonly spike during these times. Our group will investigate the expansion of data collection to include non-social care codes in 2023/24.

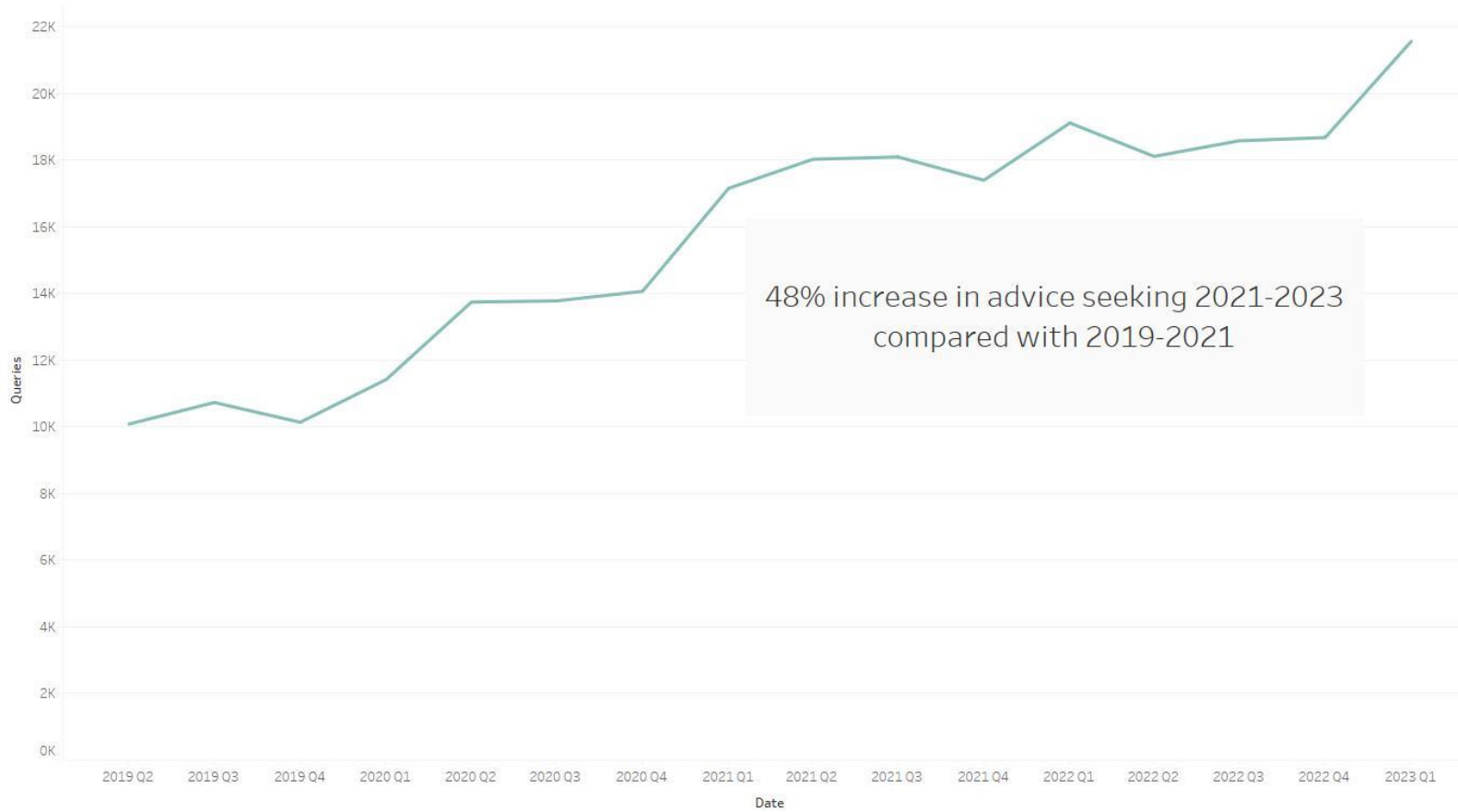
Of those queries that increased into the emergence of COVID-19, some have stabilised at a higher rate than pre-pandemic. This year, through our semi-structured interview process with our members, we can give further examples and case studies as to examples within the above universal themes.



Information seeking

Information seeking queries relate to social care information seeking only.

Information seeking
2019 - 2023

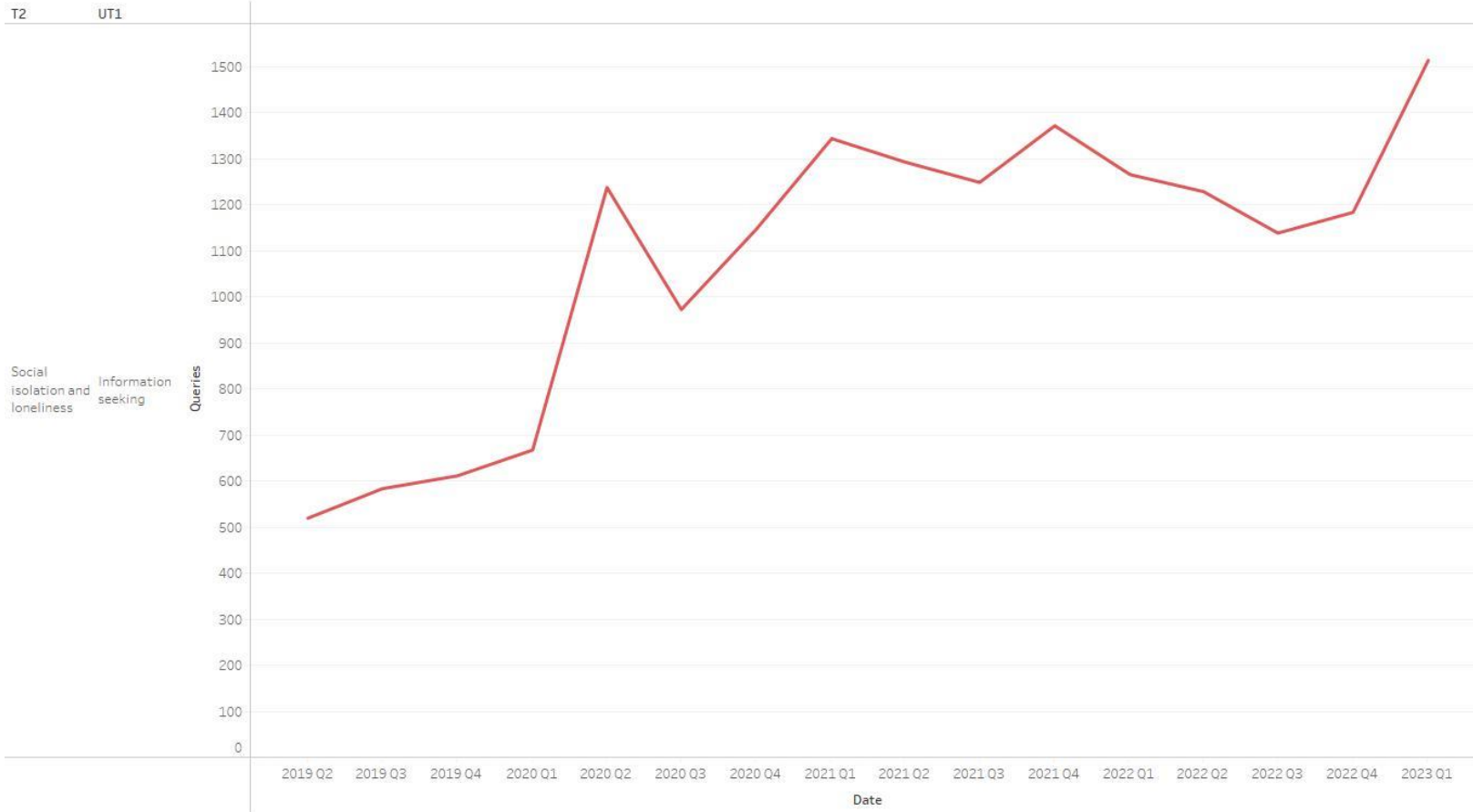


Our project does not yet categorise a second level of themes within Information Seeking, so our data on this theme is expanded on particularly through semi-structured interviews with our members.

Analysis of our members' own internal codes demonstrates concerning and ongoing rises in relation to social isolation and loneliness.

Information seeking

Social isolation and loneliness



Access Social Care Case Study: social isolation

Access Social Care supported T, a person in their mid 30s with a diagnosis of autism, bipolar and osteoarthritis. They were allocated four hours of 1:1 support per day three years ago. This was previously used for a short amount of time to get ready to go out, and mainly at their day centre a few days a week. T's needs had significantly escalated since the date of their last assessment and care plan, and their care provider had repeatedly requested reviews to the social worker. 18 months had passed since the first request for review. T was told that there was a delay and a shortage of social workers but that they were on the list. All of T's 1:1 hours of support were now being used to provide personal care at home, which left nothing to support them to access activities in the community or to meet with friends at their day centre. T was severely depressed and gained significant amounts of weight, unable to leave their home and see their friends which further impacted their osteoarthritis. The resulting pain was additionally having a detrimental impact on T's wellbeing. We supported T and their family member to raise these concerns with the local authority.

We set out below the sheer number of people on waiting lists for an assessment, an update to their care plan or awaiting a review. As the Spring 2023 ADASS report highlights: *"Some of these people will inevitably deteriorate whilst waiting, either becoming ill and needing hospital or relying on unpaid carers"*¹¹

Citizens Advice Case Study: social isolation

A local Citizens Advice advised a person with a health condition who did not have access to any social care or community support. They had approached Citizens Advice in relation to cost of living problems and complex debt issues. The advisor established that the client was extremely socially isolated and could not afford food. Advice was given on pathways to access further support in addition to food bank vouchers.

Information provision is a local authority duty detailed under s4 Care Act 2014 and Chapter 3 of the Care and Support Statutory Guidance¹². Paragraph 3.3 of the Statutory Guidance states: *"The local authority has an active and critical role in the provision of information and advice and must take an active role. To fulfil its duty under section 4 of the Act, a local authority is likely to need to go further than providing information and advice directly (though direct provision will be important) by working to ensure the coherence, sufficiency, availability and accessibility of information and advice relating to care and support across the local authority area. Importantly, this duty to establish and maintain an information and advice service relates to the whole population of the local authority area, not just those with care and support needs or in some other way already known to the system."*

Our members report that cases within the information seeking category can regularly be complex and multi-faceted. What may present as a single debt issue, for example, will require advice (and sometimes specialist legal advice) on three to four areas of need. Without holistic advice addressing all issues, the person is often unable to make progress.

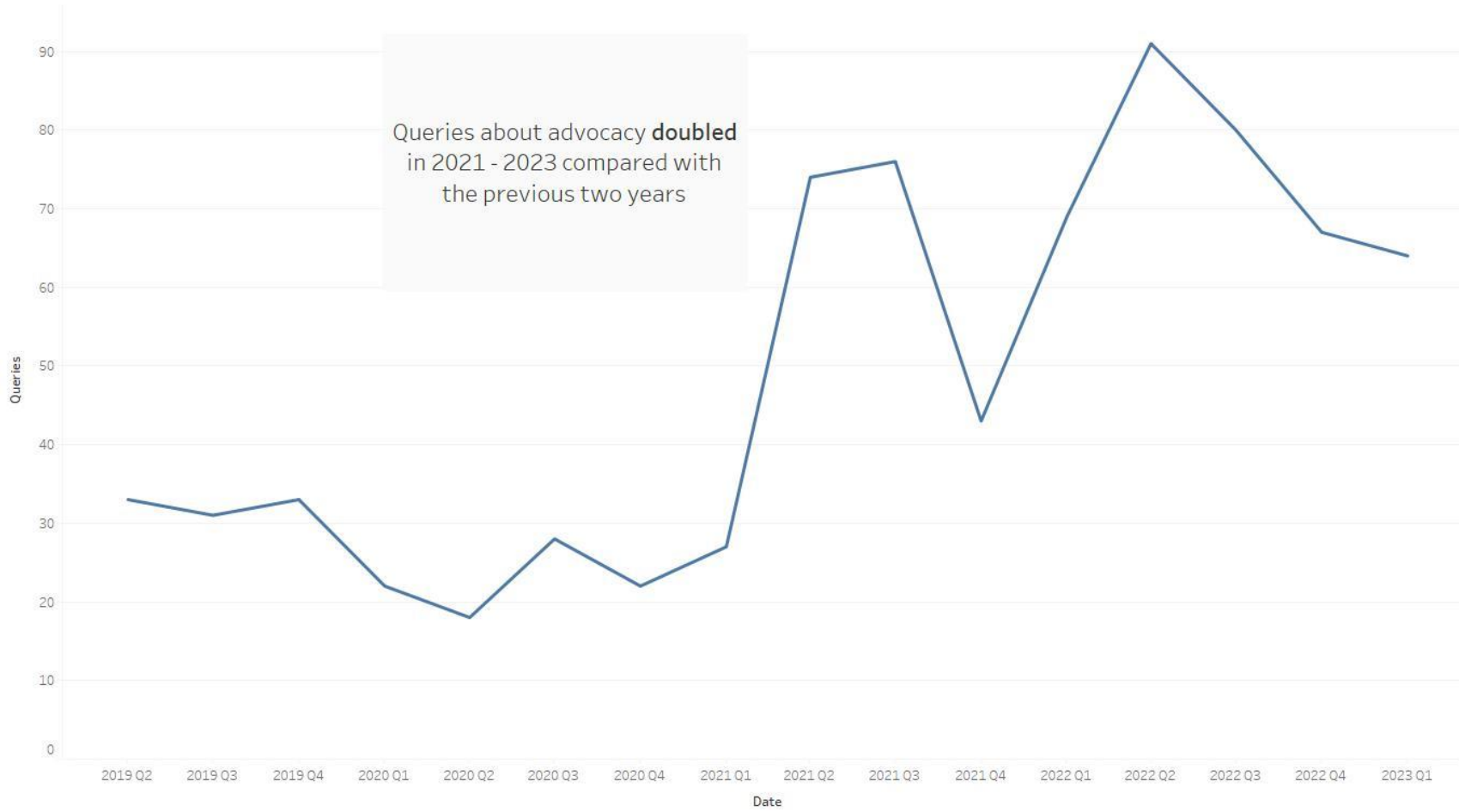
No information provision data in relation to s4 Care Act 2014 duties is collated by or reported on by central government.

¹¹ [adass-spring-survey-2023-key-messages_conclusions_recommendations-1.pdf](#) page 3

¹² [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](#)

Advocacy

Advocacy
2019 - 2023

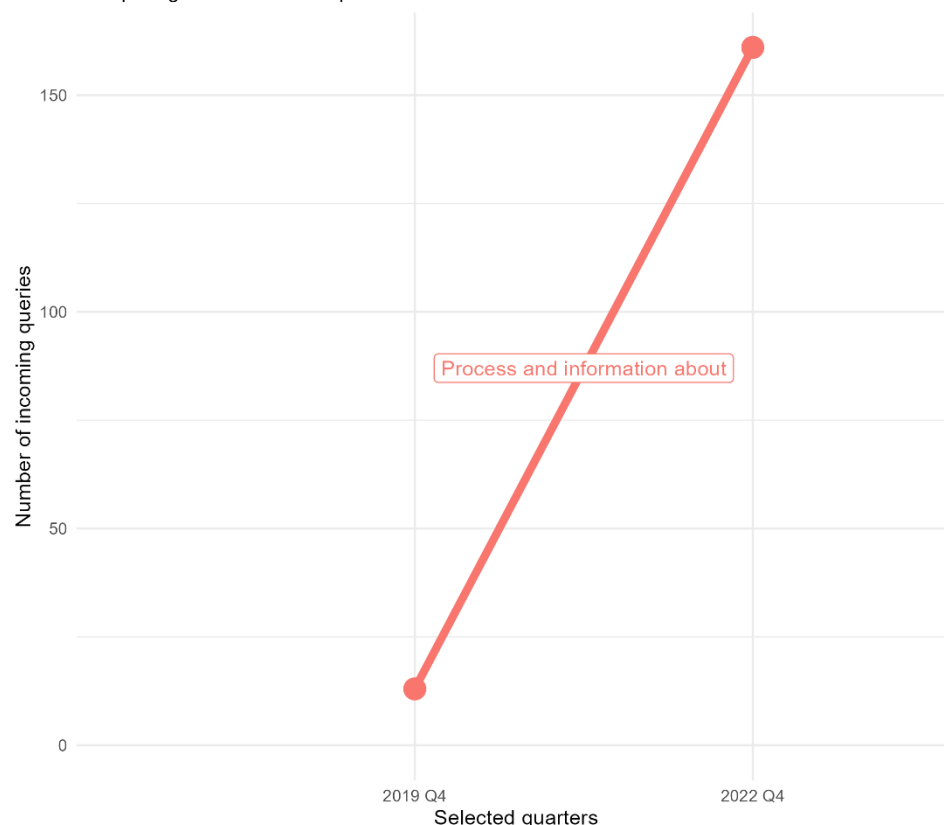


There is no government data collection on the use of Care Act 2014 advocacy services, and the latest Independent Mental Capacity Advocacy data has not been updated since 2014¹³. It is not possible to truly understand the level and nature of people’s needs in many cases without this data, and it is an important measure which could be combined into future ongoing data capture in line with the government’s 2022 Data Saves Lives Strategy¹⁴.

These statutory services are required where a person (or their informal carer) would otherwise have ‘substantial difficulty’ taking part in the care and support process. The test is distinct from whether a person has mental capacity. It is therefore an integral part to ensuring that an individual’s voice is heard by statutory services when making pivotal decisions about whether someone should get care and support, and what that should be. Some of these will be simple questions asking how to access statutory advocacy services but will also include queries about what to do when someone has been refused an advocate. Some enquirers report that they are simply told that they (or more often their family member/friend) have capacity to take part in the care process so do not require an advocate. However, in reality, they will struggle to meaningfully take part and would have substantial difficulty in doing so alone.

As we observed in our last State of the Nation report, our members have continued to see steep rises in queries relating to advocacy. We are concerned to observe a relatively stable number of queries prior to 2021 Q1, after which there is a marked spike in which the number of incoming queries effectively doubles. This doubled rate remains visible until present, indicating that the need for advocacy advice is remaining higher to pre-pandemic levels. This is something that our group will continue to monitor into 2023.

Selected UT2 topics for the UT1 topic: Advocacy
Comparing before and after pandemic



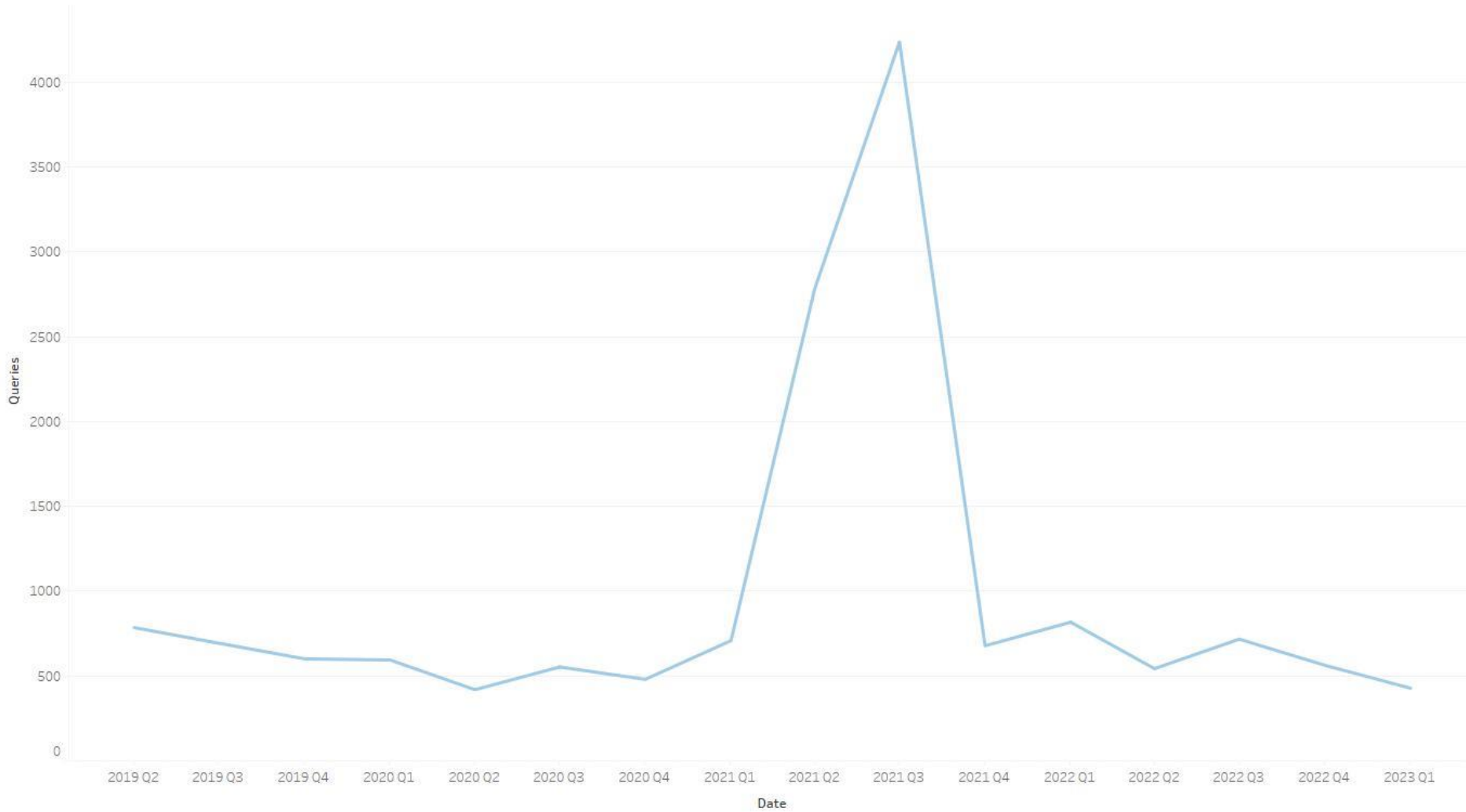
Organizations with data missing in 2019 Q4: Access, Age UK, Carers UK, Independent Age, SCOPE
Organizations with data missing in 2022 Q4: Carers UK, Independent Age
Values lower than 5 are rounded to 5

¹³ [GSS adult social care statistics interactive database \(civilservice.gov.uk\)](https://civilservice.gov.uk/gss-adult-social-care-statistics-interactive-database)

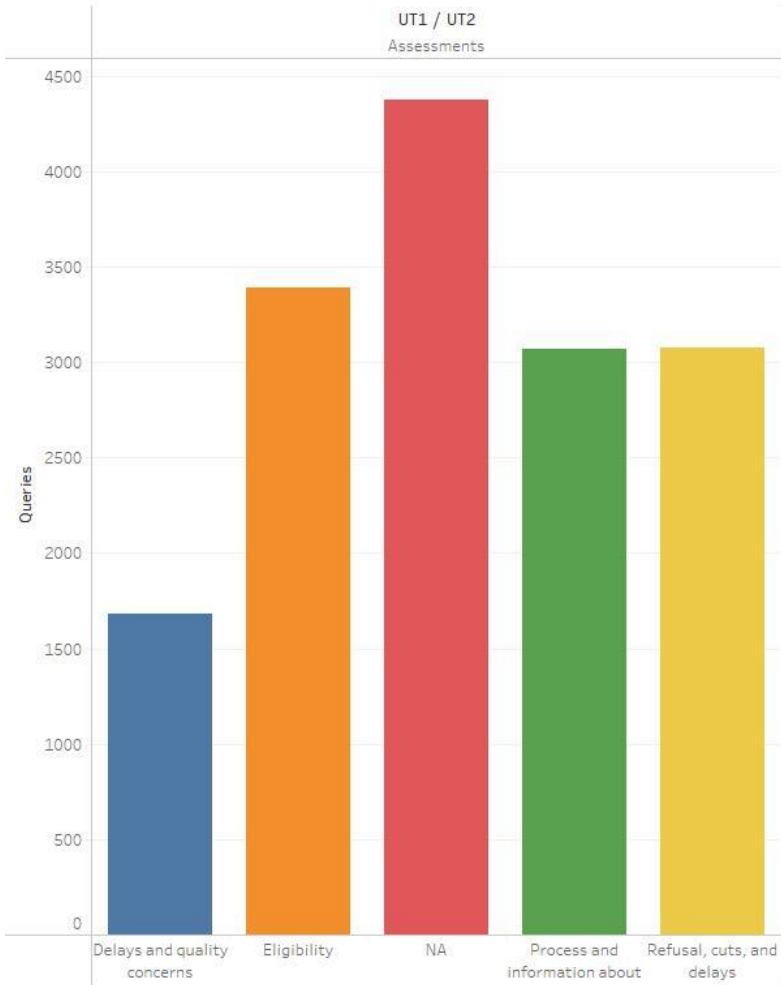
¹⁴ [Data saves lives: reshaping health and social care with data - GOV.UK \(www.gov.uk\)](https://www.gov.uk/data-saves-lives-reshaping-health-and-social-care-with-data)

Assessment

Assessment
2019 - 2023



Assessment: common themes
2019 - 2023



UT2 topics for the UT1 topic: Assessments
Comparing before and after pandemic



Organizations with data missing in 2019 Q4: Access, CAB, Carers UK, RNIB, SCOPE
Organizations with data missing in 2022 Q4: Age UK, CAB, Carers UK, Ealing Advice Service Consortium, SCOPE
Values lower than 5 are rounded to 5

Assessment

The assessment and eligibility process is one of the most important elements of the care and support system. The process must be person-centred throughout, involving the individual and those supporting them to have choice and control. The assessment process starts from when local authorities begin to collect information about the person and will be an integral part of the person's journey through the care and support system as their needs change. It is a gateway to care and support that individuals need in order to live fulfilled lives. It can also be a critical intervention in its own right, which can help people to understand their situation and the needs they have, to reduce or delay the onset of greater needs, and to access support when they require it.

The significant increase in assessment queries has stabilised since our last State of the Nation report in 2022. The spike in queries has driven the 123% increase in in assessment queries in 2021 – 2023 compared with 2019 – 2021. The latest Adult Social Care Activity and Finance Report¹⁵ shows that 2021-22 saw 179 more people every day requesting social care support. Queries have stabilised into 2022/23. We set out below that almost half a million people are still awaiting assessment or the provision of care and support: demand is still significant. Members report that some enquirers have been put off seeking a social care assessment because they have incorrectly been told they will have to pay an unaffordable amount for care, or in other cases have been told that certain types of care are not available. Other members have reported that some enquirers have been waiting for so long that they begin to lose trust in the system and lose hope that pursuing an assessment or care plan will make a difference. Some of these factors may contribute to the current level of assessment queries and we will monitor this into 2023.

Members report that the spike seen in contacts to their helplines was heavily driven by people making plans about their care following the first and second waves of the COVID-19 pandemic: many people had altered their care packages at the start of the pandemic, for example moving back in with family or changing the way in which they accessed the community. The impact on unpaid carers was highlighted in our last report. Many of these people, largely around the same time, then had to make plans moving forward as the second wave of COVID-19 began to decrease. Slowly, the pattern of assessment queries then began to settle. The increase in assessment queries of 229% in 2021 as reported in our last State of the Nation report¹⁶ has therefore stabilised in our members' data, but demonstrating a higher total volume of queries in 2021-2023 compared with 2019-2021. The 'NA' category represents queries about assessments where no further detail is recorded in relation to which part of the assessment process the enquirer is asking about.

¹⁵ [Adult Social Care Activity and Finance Report, England, 2021-22 - NDRS \(digital.nhs.uk\)](#)

¹⁶ [The+State+of+the+Nation+-+Monday+13th+June+-+Website.pdf](#)

The queries about assessments vary in type, including:

- Questions about **how to get an assessment** and what will happen during the assessment
- What to do when a local authority **refuses to assess** someone
- Concerns around **delay** in getting assessments or the **quality** of the assessment
- People being told verbally that they would not meet the criteria for local services but who **have not yet had a statutory assessment** under s9 Care Act 2014
- **Delays** in getting an assessment despite the local authority agreeing to carry one out (with some people being told they are on long waiting lists)
- Many carers are reporting that the support they are assessed as needing during a carers assessment is **based incorrectly only on the needs of the person they care for**, failing to consider the reality of the carers' own presenting needs

Several of our members have advised on cases where delays to assessment are causing a person to remain at significant safeguarding risks, who are either at risk of harm towards themselves or to others. The Care Act 2014 and associated statutory guidance makes provision to implement urgent interim packages pending assessment¹⁷, but in many instances, people are not told about this and must wait several months before emergency action can be taken.

The Spring 2023 ADASS Survey highlighted the difficulties local authorities face¹⁸. The survey asked Directors of Adult Social Services to indicate which statutory duties they felt **least** confident to meet: 38% selected the statutory duty to conduct assessments (relating to both 'carers' and 'people using services'). There has additionally been a **99% increase** in the number of people who have waited over 6 months for an assessment of any kind from November 2021 to March 2023¹⁹. People who may be in need of care and support or who already have a care package which requires revision have a statutory right to an assessment and/or review if they already have a care package. Despite a reported reduction of people on waiting lists (now down from 542,002 people in 2022 to 434,243 in 2023²⁰), financial resources from central government to assist local level resolution of this issue remain limited. Meanwhile, hundreds of thousands of people live with unmet needs in the community.

¹⁷ Care and Support Statutory Guidance, paragraph 13.34

¹⁸ [adass-spring-survey-2023-final-web-version.pdf](https://www.adass.org.uk/media/9751/adass-spring-survey-2023-final-web-version.pdf)

¹⁹ page 35, <https://www.adass.org.uk/media/9751/adass-spring-survey-2023-final-web-version.pdf>

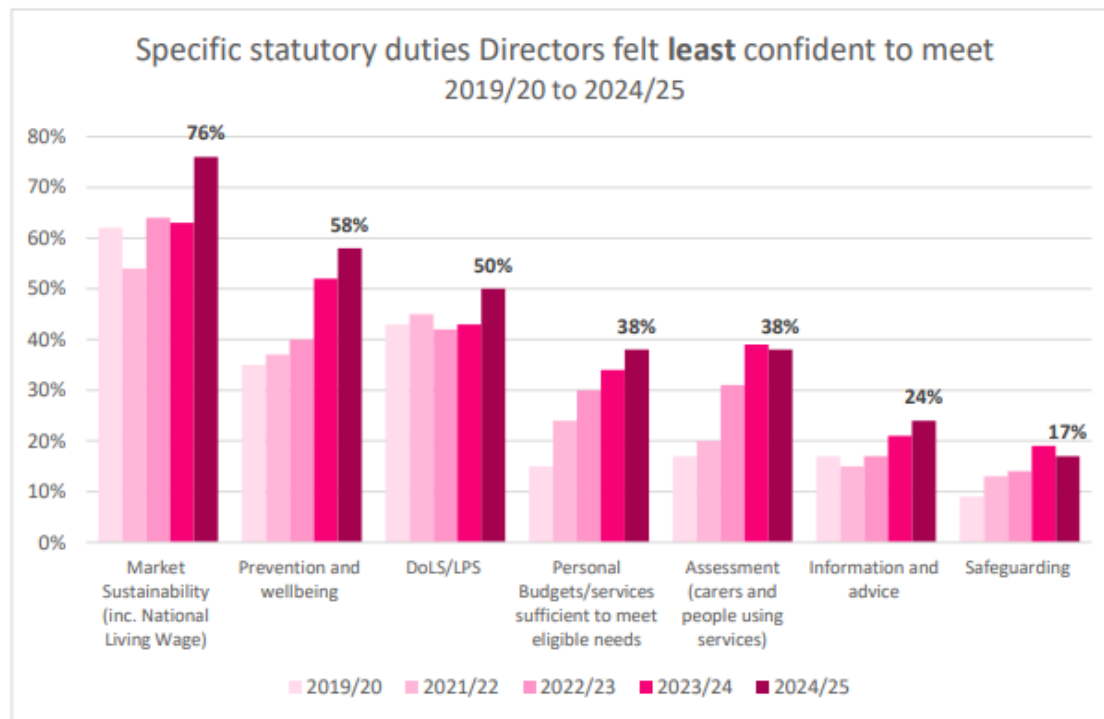
²⁰ page 36 [adass-spring-survey-2023-final-web-version.pdf](https://www.adass.org.uk/media/9751/adass-spring-survey-2023-final-web-version.pdf)

The report goes on to observe:

“Since November 2021 the number of people waiting for an assessment has increased by 10% from 204,241 people to 224,978 in March 2023. Of those people waiting for an assessment of any kind, 82,087 or 36% of people have been waiting for six months or more, an increase of 30% since 30 April 2022 and nearly double (99%) the figure reported in November 2021...

... In the past few months, the overall number of people on adult social care waiting lists for assessments, reviews, care and support or direct payments to begin has reduced by 12% during the period from 31 August 2022 to 31 March 2023. Whilst this is positive news and reflects a degree of recovery, the number of people who are waiting is at an extremely high and concerning level at 434,243 -- nearly half a million.”

Figure 16 - Which statutory duties Directors felt least confident about being able to meet 2019/20 to 2023/24 (136 responses)

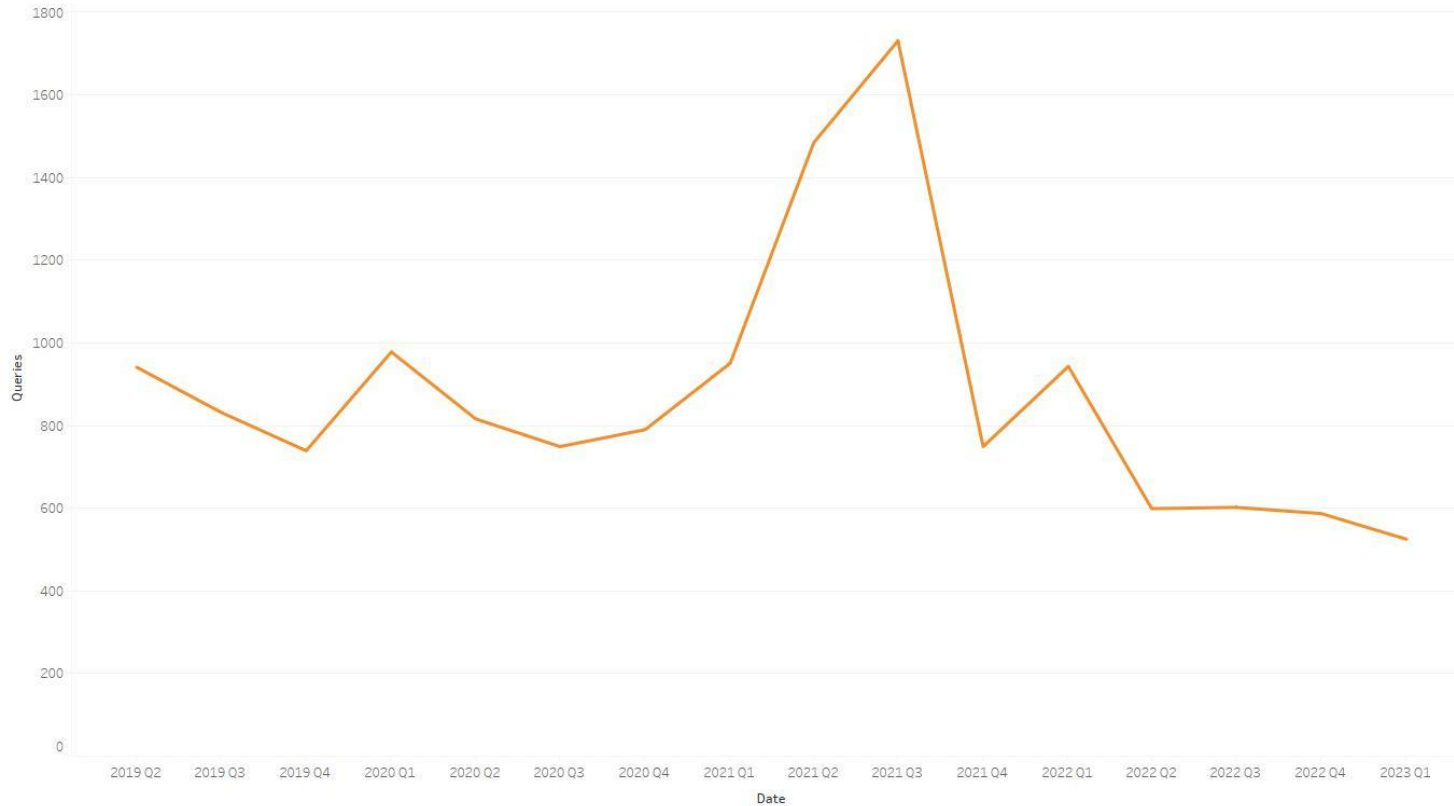


Graph from ADASS Spring 2023 report²¹

²¹ [adass-spring-survey-2023-final-web-version.pdf](#)

Care plans

Care plan
2019 - 2023



It is possible that due to the long delay in assessments and the sheer volume of people on the waiting list, queries about care plans may be reducing because less people are getting to the care planning stage. They remain stuck waiting for an assessment, as ADASS acknowledges. As with assessment issues, members report that some enquirers are told that certain types of care simply are not available or that only a certain amount of hours will be approved by panel in their area. These suggestions are often wrong, but can deter a person from having hope in seeking advice. We will continue to monitor this into 2023.

Care plans

Following the needs assessment and determination of eligibility, a plan must be provided where a local authority is required to meet needs²². Meeting needs is an important concept under the Care Act 2014 and moves away from the previous terminology of 'providing services'. This enables a greater variety of approaches in how needs can be met, developed through care and support planning as described in the Care and Support Statutory Guidance²³. Our members have reported the following common themes within care plan enquiries:

- Not being able to access a copy of a care plan, despite care and support being in place
- The care plan not being up to date in reflecting all support that is required
- Not having enough 1:1 hours in order to meet assessed eligible need
- Overreliance on shared support hours or 'core' hours within a service where this is inappropriate and would not safeguard the person's wellbeing



Unpaid carers have a right to assessment and provision of care themselves, separately from the person they are caring for. Many carers have reported increasingly that the support delivered in their own care plans is heavily based on the needs of the person they are supporting rather than their own needs. This means that the needs of the carer and the support they require are conditional on the perceived needs of the person they are caring for (as perceived by the social worker) rather than an accurate assessment of overall carer need and wellbeing. This is leaving many carers without sufficient support. Although carers have a right to an assessment to see whether they are entitled to financial support from their local authority, only a small number actually seek help. In 2021, only 8% of carers in England applied for financial support from their local authority and, of those who did, only 1 in 4 (2% of the total number of carers) ended up receiving support.²⁴

The ADASS Survey reports that although the number of people overdue a review of their care plan has reduced by 14%, there has been a 13% increase in the number of people whose Care Act reviews are overdue by 12+ months from November 2021 to March 2023²⁵. Reviews are a statutory duty under s27 Care Act

²² [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/90122/care-and-support-statutory-guidance.pdf) paragraph 10.9

²³ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/90122/care-and-support-statutory-guidance.pdf) paragraph 10.10

²⁴ [Only 2% of carers receive financial support from local authorities \(health.org.uk\)](https://www.health.org.uk/news/articles-and-opinions/only-2-of-carers-receive-financial-support-from-local-authorities)

²⁵ page 35, [adass-spring-survey-2023-final-web-version.pdf](https://www.adass.org.uk/wp-content/uploads/2023/03/adass-spring-survey-2023-final-web-version.pdf)

2014 and involve a duty to keep under review care plans generally. Access Social Care are supporting several clients who have been waiting for years for a review, even despite repeated requests due to a change in circumstances. The latest Adult Social Care Activity and Finance Report²⁶ observes:

“55.2% of clients who had been in receipt of long-term support for more than a year were reviewed within the reporting period (253,325 clients reviewed out of 458,915 clients in long-term support for more than a year), down from 58.4% in 2020-21. A number of local authorities have advised that the COVID-19 pandemic continued to affect reviews; in 2021-22, with a reduction in formal reviews taking place, due to them being de-prioritised and lack of staff available to carry them out.”

Eligibility determination and care planning concerns account for 18% of all care plan queries. People contacting helplines about care planning are becoming increasingly frustrated due to delayed care planning processes. The lack of available staff referred to above has impacted on this issue significantly, with many people informed that their allocated social worker has left and that they will not have a new named social worker but instead will fall to the ‘duty list’. This change in approach can be fraught with difficulties for people receiving long term care who find themselves unable to build a relationship of trust and confidence with duty teams who are themselves, due to the unsustainable pressure, unable to spend sufficient time with the person with care and support needs to understand their situation effectively.

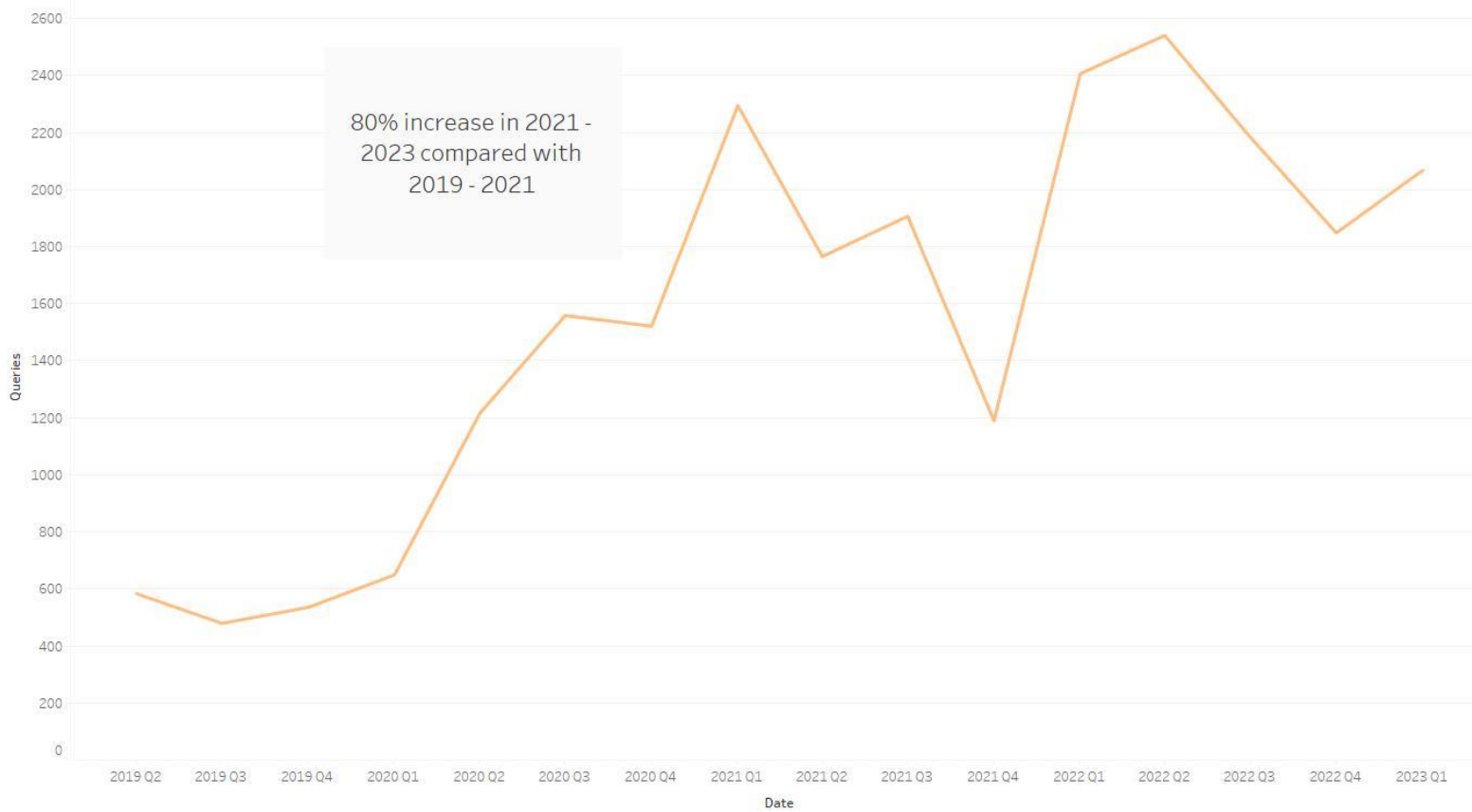
Case study: Care planning

T, a young adult looking to leave home for the first time, was assessed as being eligible for care and support in supported living accommodation with day centre attendance 3 days per week. He and his family had found accommodation near to the family home which would meet his needs and had a vacancy. His social worker told him that the care package needed to be approved by panel. 9 months later, there had been no update. The vacancy was needed by another person and it appeared likely that the placement would be lost. The social worker said it still had not been approved by panel and that there was nothing that could be done. T experienced distress and upset due to the ongoing uncertainty. T was referred to a legal aid firm for specialist legal advice.

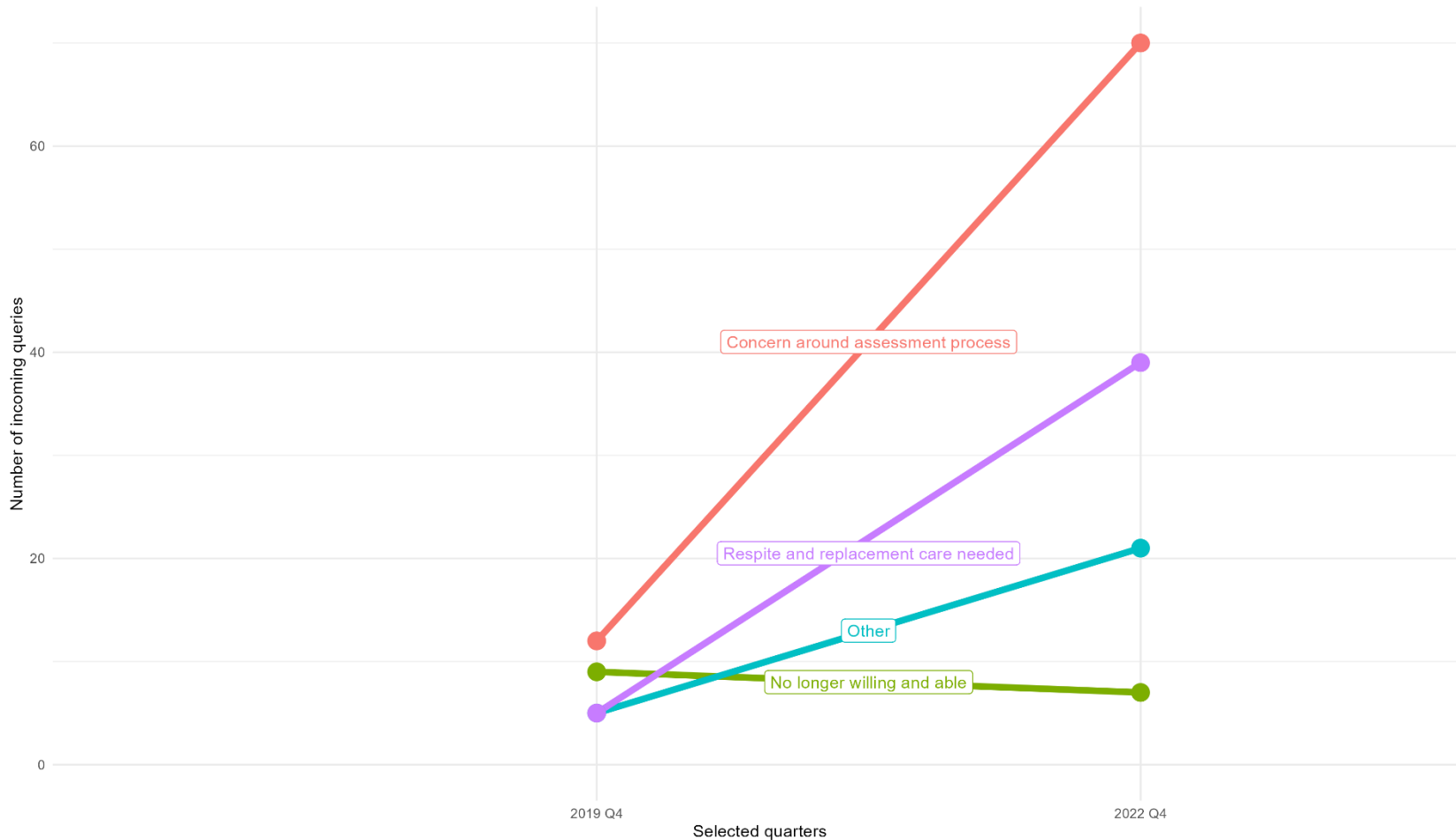
²⁶ [Reviews - NDRS \(digital.nhs.uk\)](https://digital.nhs.uk)

Carers

Carers
2019 - 2023



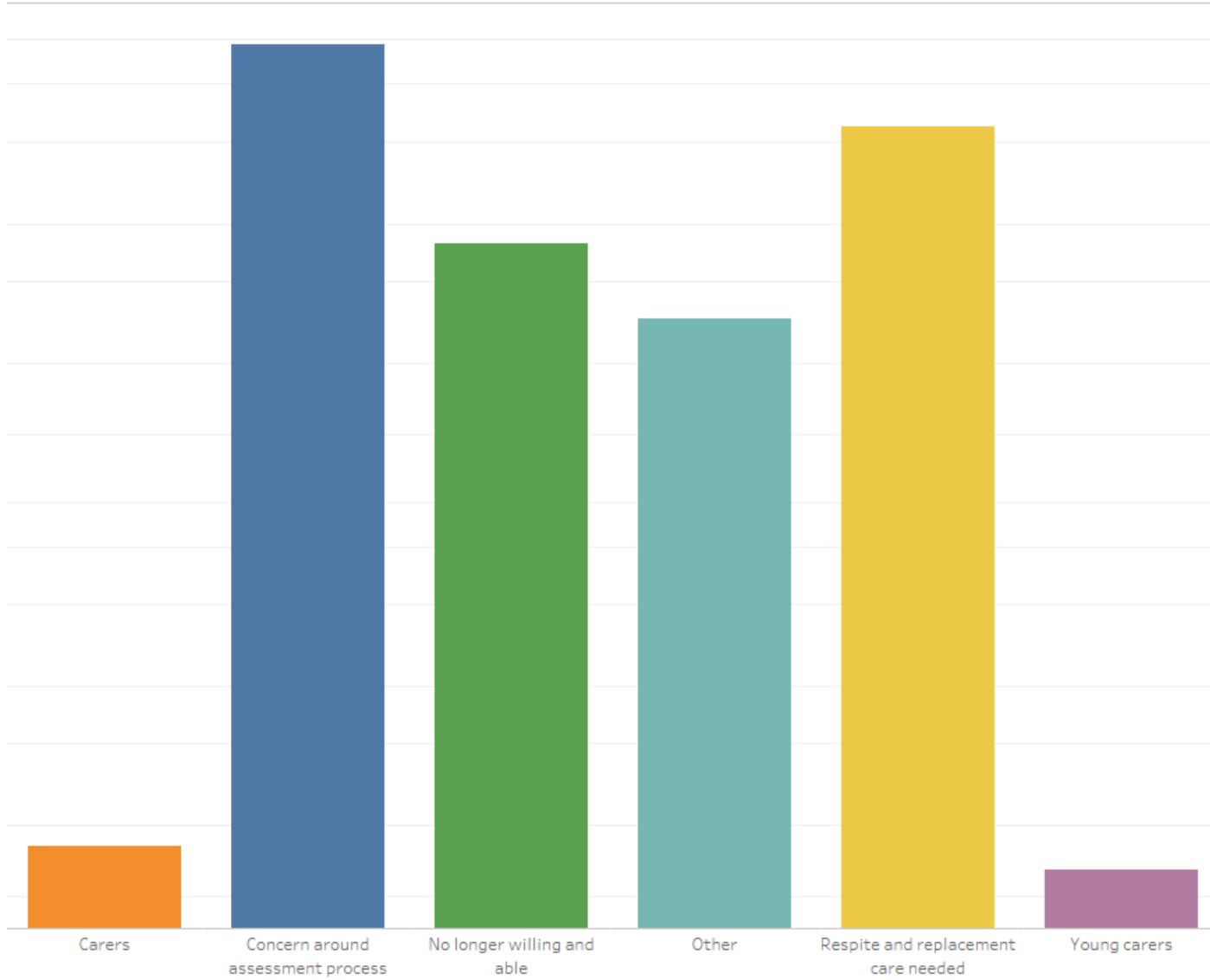
UT2 topics for the UT1 topic: Carers
Comparing before and after pandemic



Organizations with data missing in 2019 Q4: Access, CAB, Carers UK, Mencap, RNIB, SCOPE
Organizations with data missing in 2022 Q4: CAB, Ealing Advice Service Consortium, Independent Age, Mencap
Values lower than 5 are rounded to 5

The chart below shows themes ('universal theme 2') within the carers theme:

UT1 / UT2
Carers



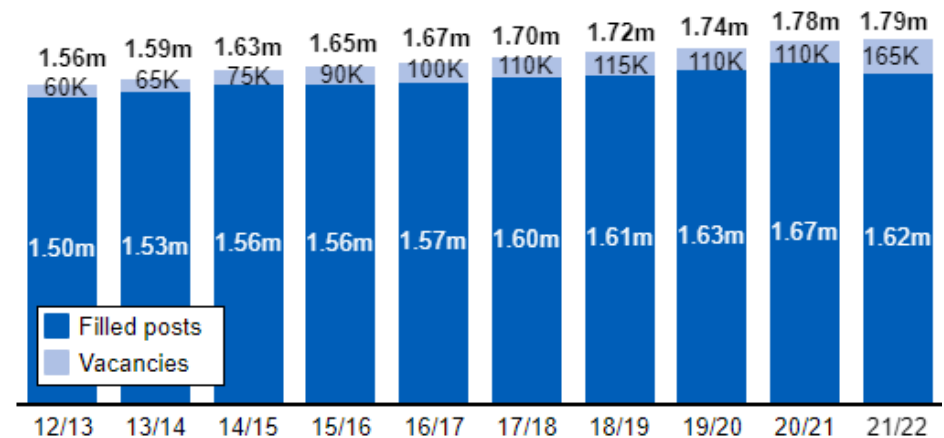
The most recent Census 2021 puts the estimated number of unpaid carers at 5 million in England and Wales²⁷ although research by Carers UK in 2022 estimates this could be much higher, and as high as 10.6million²⁸. The Association of Directors of Adult Social Services Spring 2023 report identifies that unpaid carers are being left to pick up the pieces of shortages in health and social care support to the detriment of their own health and wellbeing. 91% of Directors strongly agree or agree that unpaid carers are coming forward with an increased level of need in their local area over the past 12 months, with Directors ranking burnout as the number one reason that has contributed to an increase in carer breakdown over the past year²⁹. It is alarming to see a stabilisation or reduction in assessment and care plan queries at the same time as informal carer concerns increasing - this may suggest that people who are either awaiting assessment or have been waiting for formal care and support for months or years are essentially pushed away from the statutory care and support system and being cared for solely by largely unsupported informal carers.

Our members continue to hear from unpaid carers struggling to access support for themselves and their loved ones. Our members have continued to hear from carers who have passed the point of burnout and report feeling suicidal. Many of these carers will struggle to get an assessment, or a sufficiently timely assessment if they are at crisis point. A lot of these cases are reflected in the 'concern around assessment process' set out above. Many carers across our membership more broadly are reporting that respite and replacement care is increasingly harder to find.

For some, this is due to the workforce crisis. The workforce vacancy rate has risen by 52% since 2020/21³⁰, with 165,000 vacancies currently open. Finding a carer and maintaining a long-term working relationship with them, for many, has become increasingly difficult. Some carers report feeling so burned out and pushed back by the system that they no longer feel able to keep requesting the help that they so desperately need, particularly post-COVID.

Right: Workforce vacancies graph from Skills for Care State of the Adult Social Care sector and workforce in England³¹

Filled posts and vacancies between 2012/13 and 2021/22



²⁷ [Key facts and figures | Carers UK](#)

²⁸ [Key facts and figures | Carers UK](#)

²⁹ [adass-spring-survey-2023-key-messages_conclusions_recommendations-1.pdf](#) page 1

³⁰ [The state of the adult social care sector and workforce in England \(skillsforcare.org.uk\)](#)

³¹ [The state of the adult social care sector and workforce in England \(skillsforcare.org.uk\)](#)

Charging

Charging
2019 - 2023



Charging refers to the amount of money a person is asked to pay for their social care. The Care Act provides a single legal framework for charging for care and support. It enables a local authority to decide whether or not to charge a person when it is arranging to meet a person's care and support needs, or a carer's support needs.³²

Because a person who receives care and support outside a care home will need to pay their daily living costs such as rent, food and utilities, the charging rules must ensure they have enough money to meet these costs. After charging, a person must be left with the minimum income guarantee (MIG), as set out in the Care and Support (Charging and Assessment of Resources) Regulation 2014. In addition, where a person receives benefits to meet their disability needs that do not meet the eligibility criteria for local authority care and support, the charging arrangements should ensure that they keep enough money to cover the cost of meeting these disability-related costs.³³

Enquiries about charging include:

- When a financial assessment should take place
- Disability related expenditure, the amount a local authority should disregard in calculating care charges
- Not being able to pay for care charges
- Being invoiced a large, backdated sum for care and support without understanding how the local authority had arrived at that figure

Access Social Care research indicates that many local authorities are seeking to use charging as a way of attempting to balance their adult social care budget. Our members have been hearing from people who have been told they will now have to pay more money for their care and support, with no explanation as to how the additional costs have been arrived at. Disability Related Expenditure is often not fully taken into account. Many Access Social Care clients report that they would not have known that they could challenge these decisions were it not for our support – this raises concern about the overall pattern of charging queries in our data and naturally raises the question as to whether people truly understand their legal rights in relation to the charging process. These costs are then considered when a local authority calculates the amount of money a person should pay for their social care. The process is designed to make sure that a disabled person really does have enough money left to live on after paying for their care and support. Failure to address this issue means that care can become unaffordable for those making contributions to their care package.

³² [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](http://www.gov.uk) paragraph 8.1

³³ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](http://www.gov.uk) paragraph 8.42

In February 2023, data from 79 of 152 local authorities in England - obtained by the BBC through Freedom of Information requests - showed that councils began more than 60,000 debt collection procedures against social care claimants living in the community in 2021-22³⁴. Disabled people told the BBC they felt they had little choice but to live without home care, while others said they feared bailiffs being called in over unpaid debts. Delays in raising the Minimum Income Guarantee to reflect inflationary rises to the cost of living will have pushed many into poverty.

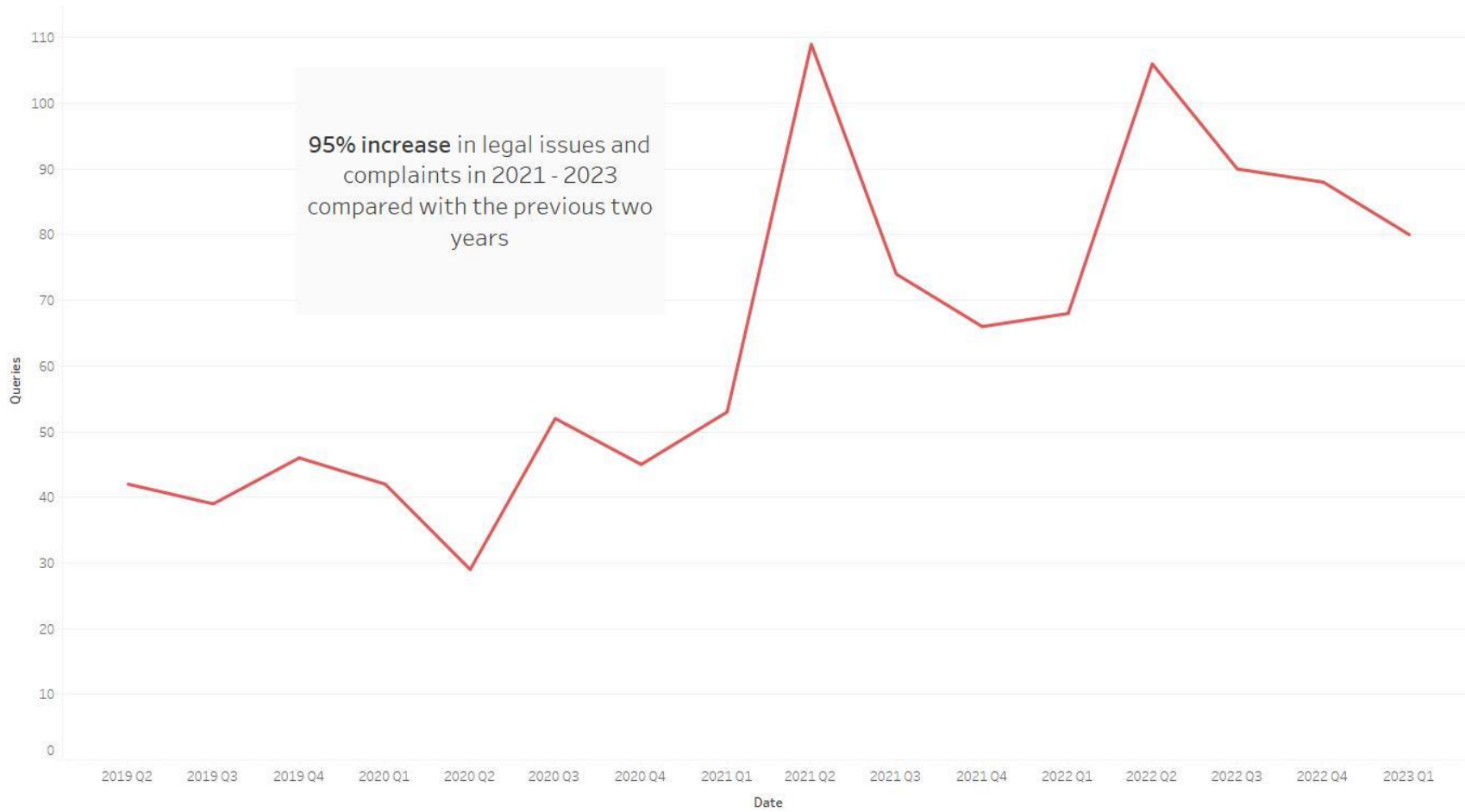
People in this situation continue to face bleak prospects of choosing to pay for care, their food, bills or vital therapies to support their wellbeing which are not available through health services.



³⁴ [Social care costs see thousands chased for debt - BBC News](#)

Legal issues and complaints

Legal issues and complaints
2019 - 2023



The number of people contacting our members for advice on how to access specialist legal support increased by 95%.

People may need specialist legal support to understand and enforce their legal rights. They may need advice on whether their case should, for example, be heard in the Court of Protection, or whether there are any other public law remedies that may be a helpful route of redress. More people are reporting that they are experiencing problems with social care issues, for example the significant increase in assessment problems detailed above.

Against the backdrop in this increase in need, there has been a staggering 77% decrease in people accessing community care legal aid since 2010. Our research³⁵ shows that accessing legal aid for community care law has become increasingly difficult because it is loss-making for law firms, meaning many people in need of this specialist legal advice are unable to access it. Some people affected by problems detailed within our set of universal themes require specialist legal advice on these complex issues. Many of our members signpost or refer to specialist law firms. However, we know from our Career Pathway Report that there has been a 77% reduction in the number of new community care cases opened in the last 10 years, with lawyers telling us that it is loss-making to take many of these cases on. We also know from Law Society research that 67% of the population, or over 40 million people, do not have access to a Community Care legal aid provider in their local authority area.³⁶

Local Authorities have two competing legal duties - one is to issue a balanced budget, the other is to meet individuals assessed and eligible social care needs. With the latest ADASS survey indicating that Local Authorities are struggling to meet their legal duties to meet even basic social care needs, it is extremely concerning that people are struggling to access justice to enforce their rights and hold public bodies to account. Without access to justice the right to social care might as well not exist.

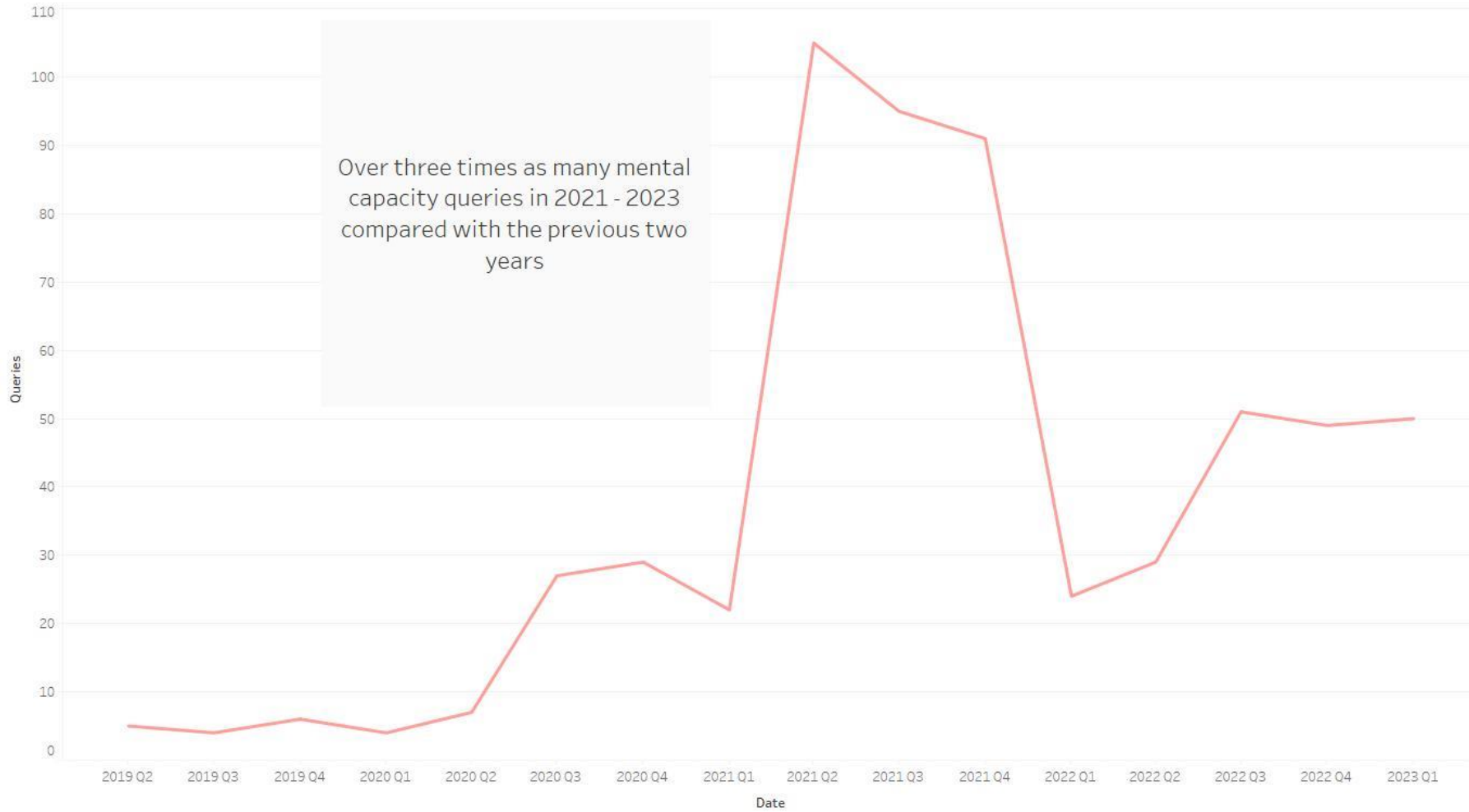


³⁵ ['Loss-making' rates behind decline in community care work | News | Law Gazette](#)

³⁶ [Community care – legal aid deserts | The Law Society](#)

Mental capacity

Mental capacity
2019 - 2023



Members saw 375% more mental capacity queries in 2021-2023 compared with 2019 – 2023. Mental capacity is a measure of someone's ability to make a decision for themselves. Mental capacity assessments look at whether a person can go through the process of making an informed decision. The majority of the increase in mental capacity queries came from older people or their families, increasing in the first and second waves of the COVID-19 pandemic but notably stabilising at a higher rate than pre-pandemic figures.

The types of queries around mental capacity include:

- Whether a person has capacity to decide to choose where to live (for many older people this often involves an assessment capacity in relation to entering residential care)
- Concern over best interests decision making processes
- Concern over Deprivation of Liberty Safeguards processes not being followed correctly
- The right to Independent Mental Capacity Advocates

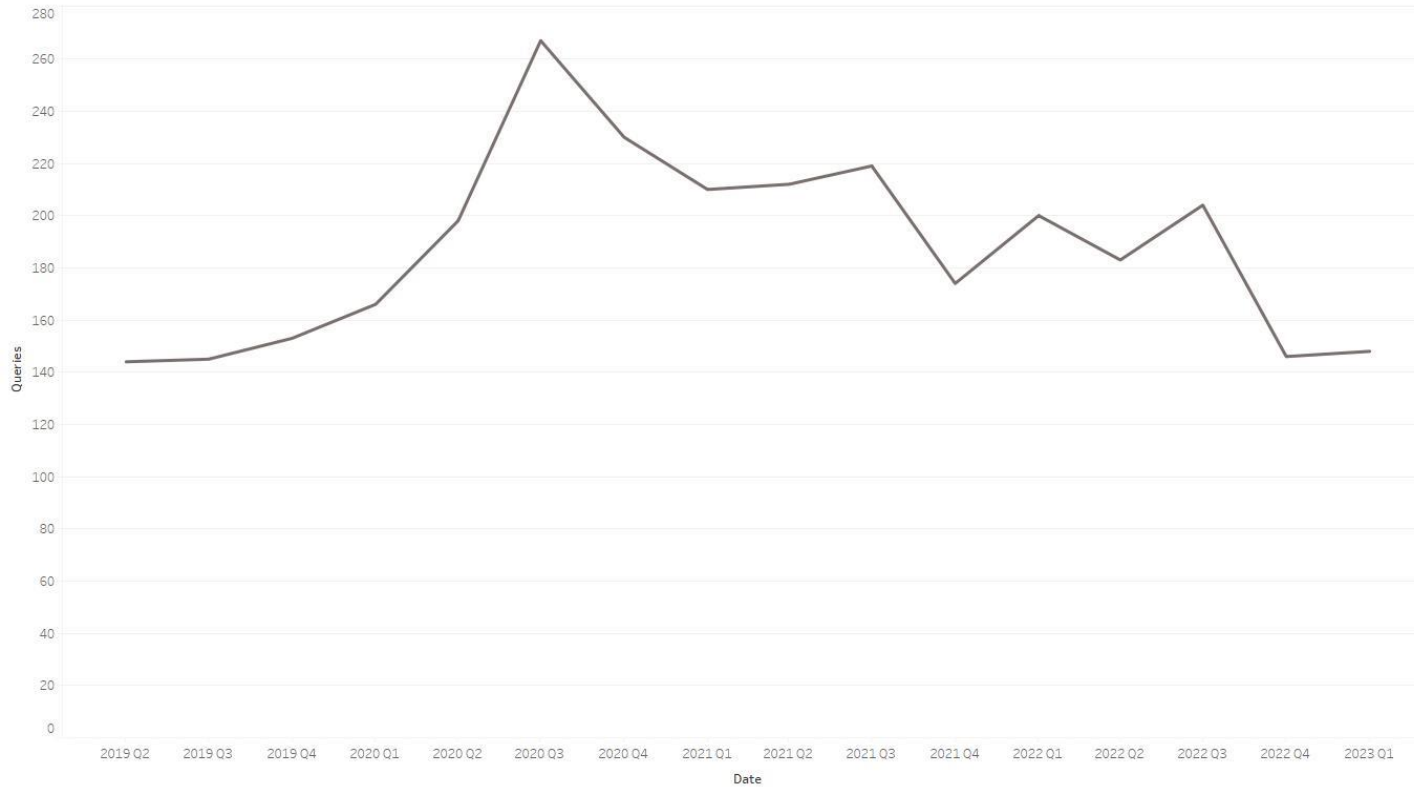
While mental capacity queries make up a smaller element of our overall dataset, disputes over mental capacity can, in some circumstances, lead to the most significant breaches of an individual's liberty or can put an individual's safety at risk. These decisions can include whether a parent with a learning disability should be allowed to parent their child, locking an individual in their room at night, and making decisions about where an individual should move to in order to receive care. We note that following an initial spike of mental capacity queries, the volume of calls each month has stabilised but at a higher level than seen pre-pandemic.



Safeguarding

Safeguarding is a term used to describe how we protect adults and children from abuse or neglect. It is an important shared priority of many public services, and a key responsibility of local authorities. Safeguarding is about protecting certain people who may be in vulnerable circumstances. These people may be at risk of abuse or neglect due to the actions (or lack of action) of another person. In these cases, it is vital that public services work together to identify people at risk, and put steps in place to help prevent abuse or neglect³⁷.

Safeguarding
2019 - 2023



³⁷ [SD8: Office of the Public Guardian safeguarding policy \(web version\) - GOV.UK \(www.gov.uk\)](#) Paragraph 4.1 and 4.2

Deprivation of Liberty Safeguards (DoLS) was the third highest area of concern in the Spring 2023 ADASS report,³⁸ with 50% of Directors ranking this as statutory duty that they are *less than confident* in meeting for 2024/25. This is likely to be impacted by the further delay by Government to the implementation of the change from DoLS to Liberty Protection Safeguards

The Spring 2023 ADASS Survey indicated that 17% of Directors felt *least confident* about meeting their statutory duties on safeguarding³⁹.

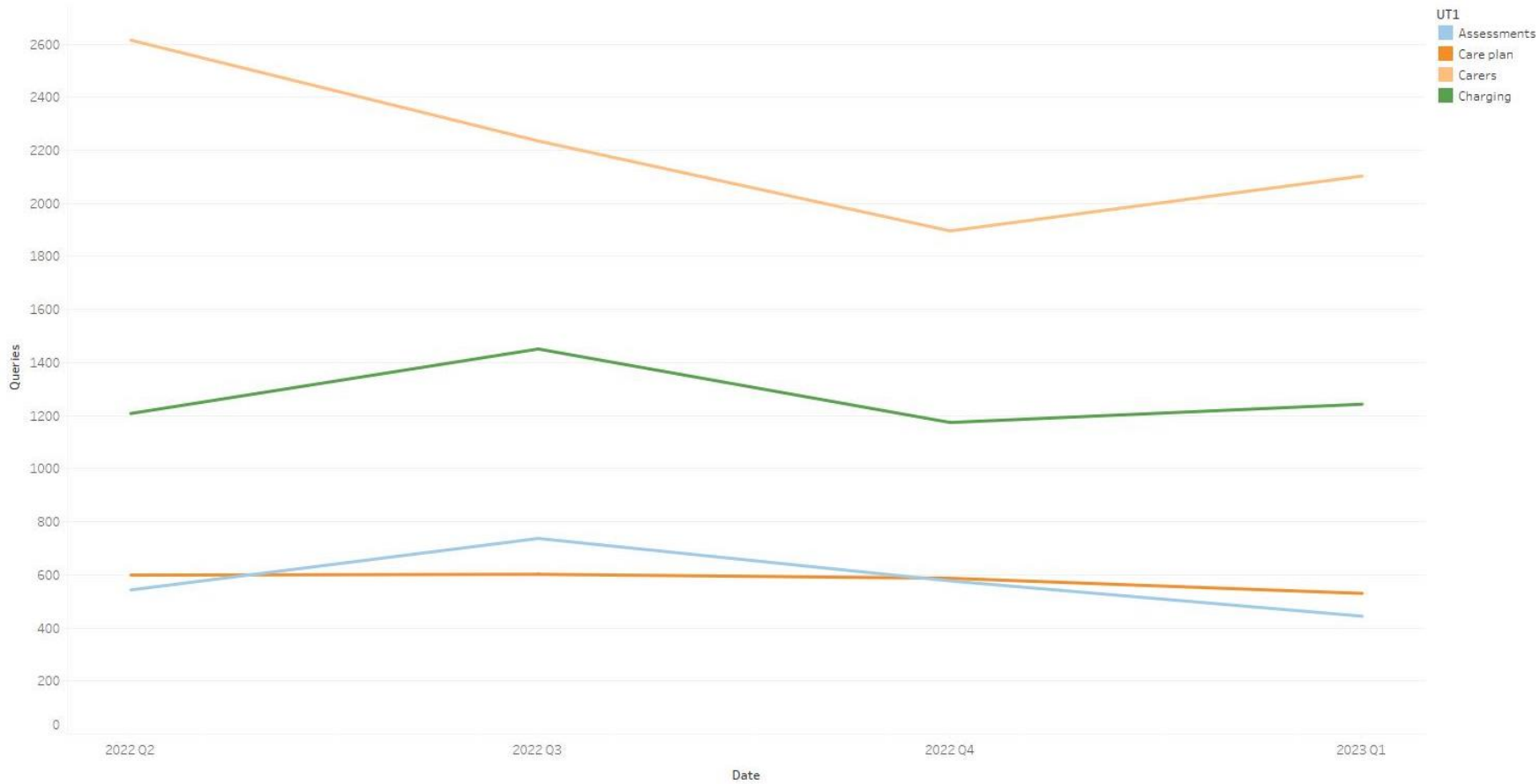
Access Social Care have observed a concerning trend in our casework on unreasonable delays in resolving even the most serious safeguarding concerns. In one shocking case, a client with a learning disability and complex health needs was drinking from his toilet. This posed a risk to life due to his health needs and yet the local authority took several months to install a protective toilet cover, despite being aware of this ongoing risk.

³⁸ page 21 [adass-spring-survey-2023-final-web-version.pdf](#)

³⁹ [adass-spring-survey-2023-final-web-version.pdf](#)

Last year in review: welcoming new members (April 2022 – March 2023)

We include in this analysis data from our physical and sensory disability audience. We are pleased to welcome disability equality charity Scope to our project this year alongside Citizens Advice. The following pages focus on the top four themes of 2022-23.



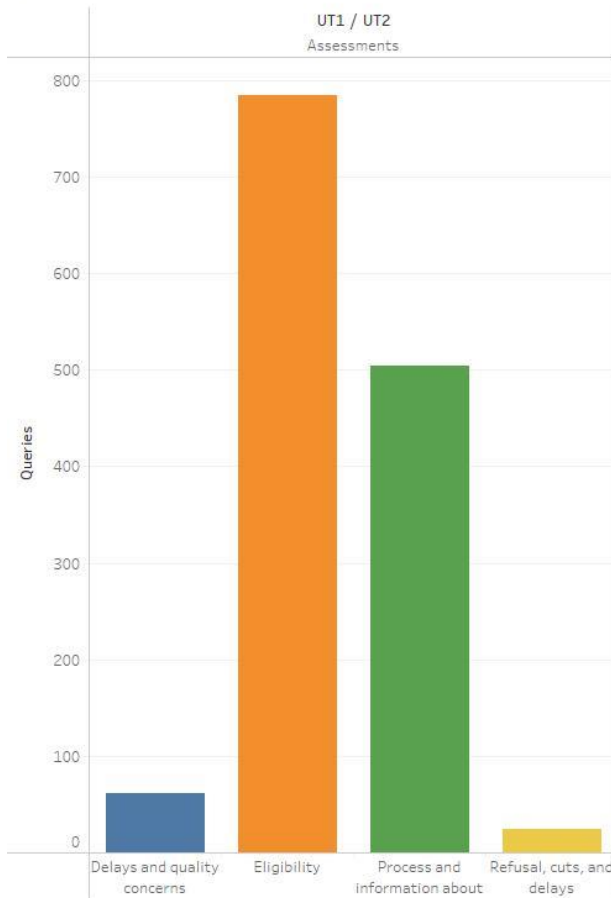
We set out above the top four occurring themes of 2022-23: assessment, care plan, carers and charging.

Assessments: 2022-2023

Year in review

Assessment themes

2022 - 2023



ADASS report that 224,000 people were still waiting for an assessment in March 2023⁴⁰. Of these people, there had been a 99% increase in people waiting 6 months or more, and a 13% increase in people waiting 12 months or more⁴¹.

Where a member collects a second tier of data within 'assessments', the top four assessment issues (pictured left) were queries about eligibility, requests for support to understand process, delays and quality concerns and some reports of refusal to carry out an assessment. Some enquirers are reporting that they have been told their diagnosis does not qualify for care and support or does not 'meet the criteria'. In many cases these statements are unlawful but driven by extremely challenging financial savings targets within local authorities. For other enquirers, they may have an assessment but can discover that their needs are not accurately reflected and therefore the care and support they are eligible for is inadequate. Others find that the assessment documentation places an over-reliance on unpaid carers, who are often unwilling or unable to continue to support the person with care and support needs.

The assessment process is integral to the legal rights of the person with care and support needs and can be a critical intervention in its own right. It is also usually the case that without an assessment of needs, the individual will not receive any social care at all. It is therefore particularly concerning that on top of the significant waiting list, 38% of Directors felt **least** confident in meeting their statutory duty of assessment⁴² going forward.

⁴⁰ page 35 [adass-spring-survey-2023-final-web-version.pdf](#)

⁴¹ page 35 [adass-spring-survey-2023-final-web-version.pdf](#)

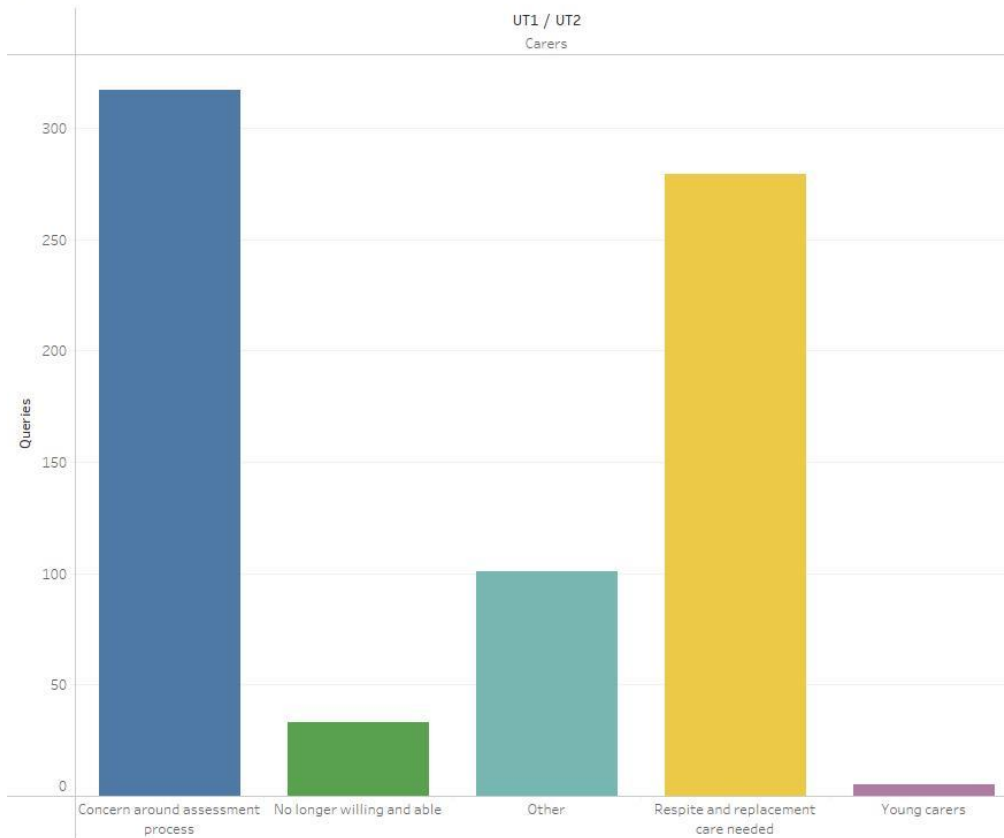
⁴² page 21 [adass-spring-survey-2023-final-web-version.pdf](#)

Care plan: 2022 – 2023

Year in review

Carers

2022-2023



Over 40% of all care plan queries related to enquirers reporting problems with care planning processes including delay, poor quality support, not having enough support in their care plan, and problems accessing care plan documentation.

Under s25 Care Act 2014, local authorities should produce a copy of a care plan. Many enquirers report they are finding it increasingly difficult to secure a copy of this care plan in breach of s25. This is concerning for several reasons, including that it makes it very difficult to access specialist advice on their legal rights. For others who have secured a copy of their care plan, they report that it no longer accurately reflects their needs. Others reported an increase in having to challenge care planning decisions, a lack of personalisation and ongoing struggles with refusals of or cuts to support.

Our members report that increasing numbers of people are getting stuck between the assessment process and the delivery of care and support. The ADASS report highlights that 22,152 people are currently waiting for care and support or direct payments to begin⁴³ - this is where an assessment has already taken place and does not include the 224,978 awaiting assessment⁴⁴, many of whom will be assessed as having eligible care and support needs. The 22,152 people awaiting support are people who have a legal right to social care and who are currently waiting in limbo for this support to arrive.

⁴³ page 36 [adass-spring-survey-2023-final-web-version.pdf](#)

⁴⁴ [adass-spring-survey-2023-final-web-version.pdf](#) section 8

Carers: 2022 – 2023

A significant number of queries relating to the universal theme of carers involved enquirers raising concern about their own assessment process. These concerns are detailed above in our thematic analysis.

Charging: 2022 - 2023

Helpline contacts relating to paying for social care have remained a key issue for enquirers this year.



Reflections and next steps

Our members are seeing concerning increases in advice demand across several of our universal themes. These developments are set against an ongoing backdrop of ever decreasing adult social care budgets.

DHSC confirmed in April 2023 that the previously planned £500m investment in workforce (set out in the People at the Heart of Care white paper) had been cut to £250m. Sarah McClinton, president of the Association of Directors of Adult Social Services, said:

"The government has a strong long-term vision for improving adult social care, but this plan leaves their vision in tatters. It ducks the hard decisions and kicks the can down the road again before the next election."⁴⁵



We are welcoming new organisations to the project – if your organisation is interested in joining us, please contact:

✉ Hannah.Hewish@accesscharity.org.uk and Amit.Kohli@accesscharity.org.uk

⁴⁵ <https://www.adass.org.uk/adass-response-to-adult-social-care-reform>

Annex A - Universal themes

Universal themes have been designed to harmonise data collected from all members. In doing so, we have designed the universal themes to reflect key duties that local authorities have in relation to people with care and support needs. These duties are reflected in the Care Act 2014 and should be key elements of the care and support journey.

Theme	Name	Definition
Universal theme 1	Advocacy	Formal support to help a person navigate the care assessment and planning process
Universal theme 2	Information seeking	Contacts to helplines encompassing a range of questions about rights
Universal theme 3	Assessment	A Care Act 2014 assessment of care and support needs for a disabled person. A precursor to receiving support, or an increase in support.
Universal theme 4	Care plans	Sets out the support needed to meet a person's eligible care and support needs (as identified first in an assessment of need)
Universal theme 5	Carers	Contacts to helplines from informal carers (or family or friends of carers) with questions about being or becoming a carer
Universal theme 6	Charging concerns	Social care charges, calculated after a needs assessment and care plan has been finalised, are assessed via a financial assessment. This looks at a person's income and expenditure and determines the amount of money they will have in their personal budget to fund support.
Universal theme 7	Direct payments	A person can choose to have their personal budget paid directly to them, or a third party, to commission their own support rather than the local authority doing this for them.
Universal theme 8	Cuts to packages	Changes or reductions made to a person's existing package of care and support.
Universal theme 10	Funding disputes	After it has been established that a person has eligible care and support needs, there can be disputes over who is the correct authority to fund this care and support. This might be based on where a person lives, or has recently moved from for example.
Universal theme 11	Mental capacity	All contacts about mental capacity related issues in the context of community care decision making.
Universal theme 12	Safeguarding	Concerns raised over the health, safety, or wellbeing of a disabled or vulnerable person.

Universal theme 13	Legal issues and complaints	Contacts where a legal issue or complaint has been directly mentioned. People receiving care and support may not know that their issue is a legal issue on contacting a helpline, and so these contacts appear relatively low. In fact, a large number of the queries received by helplines relate to legal issues most commonly within the Care Act 2014.
Universal theme 14	COVID-19	Contacts to helplines relating directly to the COVID-19 pandemic, such as problems visiting a loved one in care homes or supported living, or access to priority vaccination as an unpaid carer.

Annex B – Harmonization Process

All group members provide information and advice on broadly similar issues, but are recording their data in different ways using different categorisation methods. We studied each group member’s internal method of categorising calls and emails into their helplines. This broadly resembled two ‘tiers’ of data collection, within a primary *community care* categorisation.

Example

Community care	Assessments	Information about adult assessments
		Delay in getting assessment
		No appropriate person / advocate
		Concern around quality of assessment

Based on this analysis, we drafted a set of **universal themes** which we proposed could appropriately reflect most data collected by each group member. We convened a ‘universal themes’ workshop in July 2020, facilitated online and attended by the data leads from each group member. The aim was to collaborate with group members to co-produce a final set of universal themes which would accurately reflect each group member’s data. This was a successful half-day interactive workshop. We hosted it using an online visual collaboration platform, Miro, so that each group member could log in, navigate, and edit the board in real time:



We concluded the workshop with an agreed set of universal themes, at two 'tiers' (Universal Theme 1, for example 'Assessments', would have a Universal Theme 2 within it such as 'Refusal to carry out an assessment'). All incoming datasets could be mapped against these themes, and we created a mapping document to be used in the data processing pipeline.

When Access Social Care receives data from all members, non-social care data is considered 'outside of scope' and therefore filtered out in the initial stages. 'Within scope' social care data is then processed to assess whether it fits within the universal themes which the group collects. Not all data matches these themes, for example data about children's social care. This data appears to be social care related but is then filtered out within a second stage of processing to ensure that all data does map to each universal theme.

Annex C - Data Processing

quarter	Access	Age UK	CAB	Carers UK	Ealing Advice				
					Service Consortium	Independent Age	Mencap	RNIB	SCOPE
2019 Q1	✓			✓	✓				
2019 Q2		✓	✓	✓	✓		✓	✓	
2019 Q3	✓	✓	✓	✓	✓		✓	✓	
2019 Q4	✓	✓	✓	✓	✓		✓	✓	
2020 Q1	✓	✓	✓	✓	✓		✓	✓	
2020 Q2	✓	✓	✓	✓	✓		✓	✓	
2020 Q3	✓	✓	✓	✓	✓		✓	✓	
2020 Q4	✓	✓	✓	✓	✓		✓	✓	✓
2021 Q1	✓	✓	✓	✓	✓		✓	✓	✓
2021 Q2	✓	✓	✓	✓	✓		✓	✓	✓
2021 Q3	✓	✓	✓	✓	✓		✓	✓	✓
2021 Q4	✓	✓	✓	✓	✓		✓	✓	✓
2022 Q1	✓	✓	✓	✓	✓		✓	✓	✓
2022 Q2	✓	✓	✓	✓	✓		✓	✓	✓
2022 Q3	✓	✓	✓	✓	✓		✓	✓	✓
2022 Q4	✓	✓	✓	✓			✓	✓	✓
2023 Q1	✓	✓	✓	✓			✓	✓	✓

The table above shows what datasets are included from our partners. In phase one of our first pilot study (2019), we processed 7,000 separate contacts (each an individual enquiry). During phase two, we grew the project to 25,000 lines of data. Our last State of the Nation report was based on over 74,000 separate contacts. This year, we have processed 364,000 separate queries within our analysis.

Each individual organisation sent a spreadsheet to us containing:

- Date of enquiry
- Tier 1 code
- Tier 2 code (optional)
- Tier 3 code (optional)
- Local Authority (if available)
- Unique ID / reference number for each contact. This unique ID number is often allocated to an individual (the person contacting the helpline). While treatment of unique IDs varies by organization, there are some overall observations we can make about deduplication.
 - Multiple topics: If the person discusses several topics, they typically come in as several rows. For our purposes, it is valid to count each of these calls as valid for their topics, but when we aggregate all queries, we only count the conversation once.
 - Multiple calls the same day: In some cases, the same person will call the same helpline and discuss the same topic. If we observe the same person calling the same helpline about the same topic, we only count the calls once.
 - Multiple calls on different days: If the same person contacts the helpline again on different day, this will be logged as a separate query with a separate unique ID. Because of this processing decision, all volume reported are to be considered as 'individual queries' as opposed to 'individuals'. This will appear in our data as a duplicate ID, but can reflect that the same person has made contact about a different issue.

The data is cleaned, for example, by correcting spelling errors in Local Authorities, and ensuring dates are formatted consistently.

We then add the universal themes by mapping them to the organisation's tier code and, where possible, add local authority data and ONS geographic codes.

We then output a cleansed and consistent dataset of all organisations.

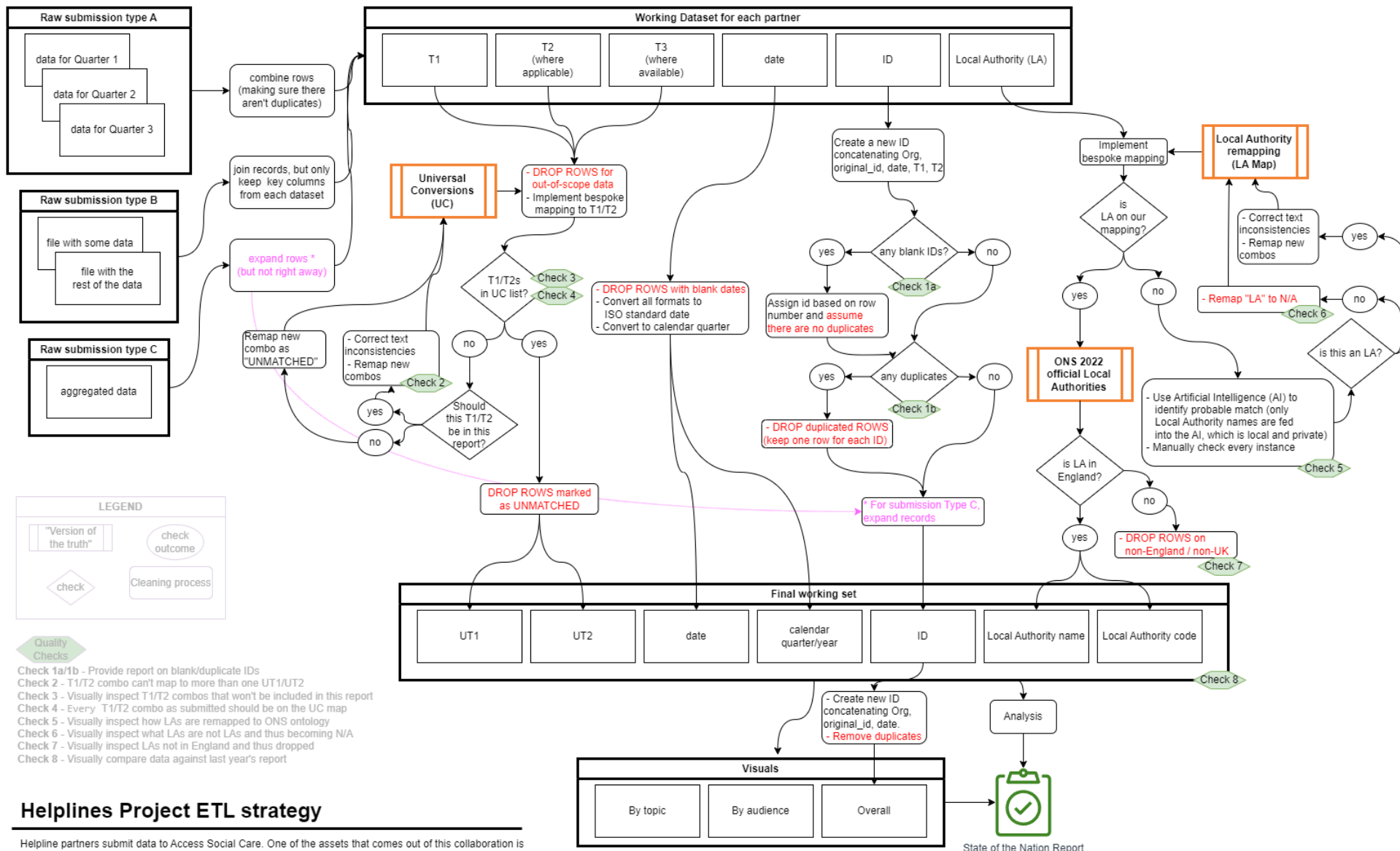
Special attention is dedicated to understanding IDs. Partners provide data at different levels of granularity... some partners use a unique ID (uID) for each topic of each conversation with clients, whereas others provide fully aggregated data that needs to be expanded to be combined with data from other partners. For the majority of this report, the granularity level is person-topic-day, in other words, multiple calls with the same client on the same topic on the same day will only count once, but if the conversation involves several topics, each topic is counted individually. Top level aggregates only count the "person-day" level, such that it is irrelevant how many topics were discussed.

Because we are choosing to represent people assisted on separate days as separate queries, all the numbers in this report should reflect "individual queries", not "number of people assisted". While inconvenient, this is appropriate to minimize the dissemination of PII. This approach additionally adds greater insight into individuals with multiple and complex queries and allows us to capture the full extent of the issues they are facing.

Note on deanonymization – the minimum bin size provided in this report is 5, ie, categories that are not NA but less than 5 are displayed as 5 to prevent unintentional deanonymization of the data.

This report is the first to be using a new processing pipeline, constructed entirely in R, the state-of-the-art data processing language. Data quality checks have also been inserted, and feedback on what processing has occurred is fed back to each partner for them to improve data quality internally.

A full schematic of the Extraction Transformation Loading (ETL) process follows on the next page.



Helplines Project ETL strategy

Helpline partners submit data to Access Social Care. One of the assets that comes out of this collaboration is the State of the Nation Report. This flowchart explains how the data is processed and quality controlled.

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