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Technology Solutions to Support Young Carers and Organisations that Support them

Solution for Change
University of Glasgow

TEAM 4

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Summary

Solutions for Change is a University of Glasgow programme that provides postgraduate research students and postdoctoral researchers real-life experience in leadership, collaboration, and career development by working with community-researcher partnerships on genuine local challenges. This report summarises the work and findings from Team 4, whose aim was to understand the challenges faced by young carers and the organisations supporting them and explore how technology and digital services can address these challenges.



The organisations also highlighted several considerations necessary when adopting new technology, including simplicity of implementation, affordability and compliance with legislation.

Acknowledgements

Being part of Solutions for Change provided us with very different valuable learning experiences, from in-person training sessions on presenting, leadership, team-working and collaboration, to the actual practical experiences of running a multi-stakeholder project from beginning to end, with all the joys and stresses it brings. This opportunity would not have happened without the people behind Solutions for Change and this particular challenge and for this we thank Emma and the Scottish Tech Army (STA).

Alana from the Carers Trust and Harvey from Fife Young Carers were instrumental in helping us conduct the online survey and advertise our focus group. Nadia and Catriona planned and ran the focus group on the day — thank you both for such an excellent event. We also would like to thank all the workshop participants for giving their time, experience, and insights to help us put together the findings of this report.

Finally, we would like to thank our supervisors and line-managers who supported our participation in the programme.

1. Introduction

This report sets out the findings of a two-month long project led by researchers at the University of Glasgow in partnership with the STA. The partnership was formed through the university's Solutions for Change programme and ran over the summer of 2024.

Our aim was to understand the challenges faced by young carers and the organisations that support them and explore how technology and digital services could be used to address these challenges. We sought to fulfil these aims through a combination of desk research and first-hand engagement with the organisations that support young carers.

We hope that the information set out in this report is useful for the STA and organisations that support young carers in Scotland to help inform and adopt future tech solutions.

1.1. Who are young carers?

A young carer is a young person who helps to look after a relative, such as a parent or a sibling, with a disability, illness (including a mental health condition), or drug or alcohol problem. A young carer may be doing many of jobs in and around the home, such as cooking, shopping for food, cleaning or helping someone get dressed and move around. They may also be supporting the family member physically, such as helping them move around the house, or emotionally. The exact definition and age range of a "young carer" varies across Scotland and UK. For example, some organisations define this as someone under the age of 18 years (NHS), others define it as someone aged 25 or less (Carers Trust), and the Young Carer Grant in Scotland is available for those between the ages of 16-18.

1.2. Young carers in Scotland

Because the definition of a young carer can vary and because many young people do not identify themselves as young carers, it is difficult to give a good estimate of number of young carers in Scotland. The 2022 Scottish Health Survey estimates that there are approximately 28,000 young people aged 4-17 in Scotland that provide unpaid care for someone in their family.¹ Based on the Carers Census², young carers are slightly more likely to be female (accounting for 58% of young carers) than male (42%). However, this margin increases with age and among adults (18+) females are much more likely to be providing unpaid care. Young carers are disproportionately more likely to live in the most deprived areas in Scotland and this deprivation gradient more pronounced for young carers compared to adult carers.

1.3. Organisations supporting young carers

Multiple organisations across Scotland and the UK support young carers by providing emotional support, organising recreational days and meet-ups, or providing financial support and information and help with benefits. However, these organisations themselves often face many challenges, some of which can be met with technology. These include administrative challenges related to running an organisation effectively, such that more time could be spent on supporting the young people.

¹ [Background - Scotland's Carers Update Release March 2024 - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/background-releases/2024/03/20240301-scotland-carers-update-release-march-2024/pages/11.aspx)

² [Caring Roles - Carers Census, Scotland, 2022-23 - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/caring-roles-carers-census-scotland-2022-23/pages/11.aspx)

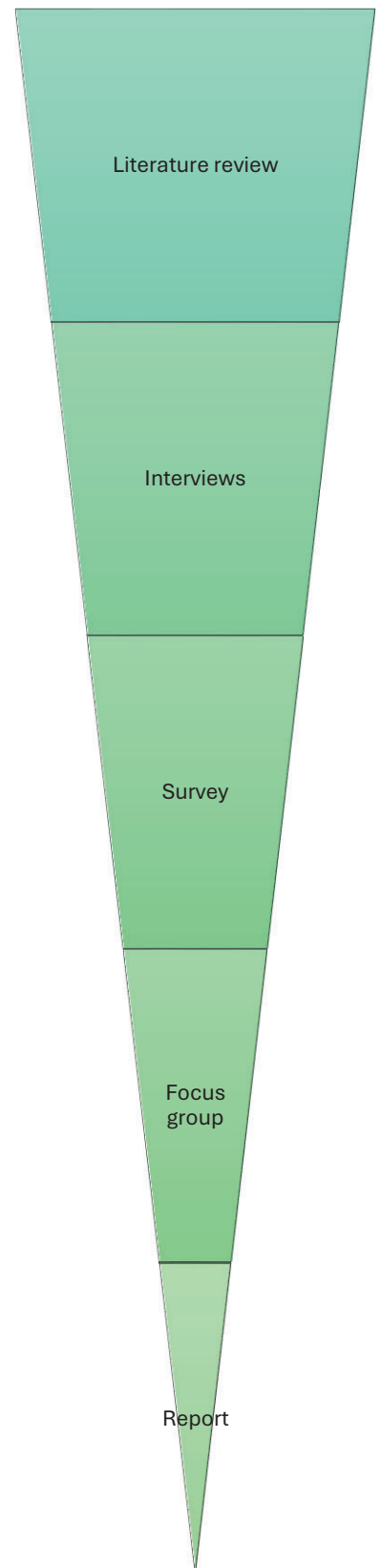
2. Our work

Throughout the project we sought to gather information from a wide range of relevant people and sources to assess common trends and identify areas where tech would be most beneficial. The work carried out can be broken down into five main steps:

1. **Literature review.** We conducted an initial literature review to understand the main challenges faced by young carers.
2. **Interviews.** We then conducted initial interviews with a few organisations that support young carers in Scotland to better understand the challenges on the ground.
3. **Survey.** Our findings from steps 1 and 2 were used to design a survey which was sent out to organisations that support young carers across Scotland. The aim was to explore how digital solutions are experienced and utilised by staff from young carer organisations. The responses captured insight, opportunities, challenges, and local innovation.
4. **Focus group.** We held an online focus group to study these issues more closely. This public engagement activity sought to gather insights from those directly involved in supporting young carers, informed by prior survey results and desk research. The group consisted of nine participants. Breakout rooms and case studies were used to encourage discussions and draw out key points. The overarching themes discussed included the challenges and barriers to implementing tech solutions, the potential benefits, existing solutions and innovations, engagement and user preference, customization of solutions, collaboration and resource sharing, and future considerations. Menti and Padlet were used throughout the session to collect thoughts on various aspects of technology solutions, fostering a collaborative environment, and shared as a resource for all participants after the event.
5. **Reporting.** Finally, we assessed and collated our findings in both report and presentation format to share with STA and the organisations that support young carers in Scotland.

Survey respondents and focus group members included employees from organizations supporting young carers, such as service managers, support workers, and other professionals involved with young carers. Participants were recruited through a combination of direct outreach, social media advertisement, and promotional efforts. Invitations were sent via email to various organizations, and our team attended a Carers Trust Chief Officer meeting to encourage participation. This approach aimed to involve a diverse range of participants with different experiences and perspectives.

The remainder for this report sets out the key findings of this work alongside our conclusions and recommended next steps.



3. Challenges

3.1. What are the challenges and support needs of young carers?

Several challenges that young carers face have been highlighted throughout this project, including:

Strains on own physical and mental health and well-being.

Young carers often report poorer health-related quality of life compared to non-carers due to the physical and psychological demands of caregiving. The stress and burden of caregiving can contribute to mental health problems such as depression, stress, anxiety, depression, and emotional exhaustion among young carers, as well as physical health problems such as asthma. Results from the Carers Census in Scotland show that nearly 90% of young carers feel their emotional well-being is negatively impacted because of their role as a young carer, about half listed advice and information, counselling, emotional and peer support as support needs. Current support systems are deemed inadequate, pointing to a clear need for accessible and targeted emotional support services.

Educational disruption and impact on academic performance.

Young carers' engagement with education can be severely disrupted due to their caregiving role. The demands of caregiving can interfere with young carers' education, leading to absences from school, difficulties in completing coursework, and potentially lower academic achievement, which has significant implications for their future employment opportunities. This can lead to a vicious circle where struggles with academic performance (due to the time and energy demands of caregiving) can lead to further absenteeism, poor concentration, and lower educational aspirations.

Social isolation.

Young carers often feel isolated from their peers due to the time-consuming nature of their caregiving responsibilities, which limits their opportunities for peer interaction, socializing and participating in recreational and normal social activities. This underscores the need for enhanced social support networks and community engagement initiatives for young carers.

Challenges in daily planning and time management.

Balancing caregiving duties with person life proves challenging for young carers, exacerbated by lack of effective scheduling and reminder tools. This challenge highlights the necessity for better planning to help manage multiple responsibilities and reduce stress.

Financial Strain.

Young carers may face financial difficulties due to the costs associated with caregiving and the potential inability to work full-time or pursue education and career opportunities.

Problems with physical Young Carers Card.

Issues related to physical young carers cards, such as loss or damage, were frequently mentioned. Transitioning to digital solutions for identification and services access could address these problems and provide a more reliable support mechanism.

Employment disruption and unemployment.

Young carers often experience disruptions in their work opportunities due to their caregiving responsibilities. Despite increased advocacy to increase diversity at the workplace and equal opportunities, young carers' employment opportunities are significantly affected. High unemployment rates among young carers may also mean that they are missing out on mentoring, support, and work engagement practices that are critical for their future employment opportunities. Explicit workplace laws protecting young carers within the first 12 months of employment are absent, and reasonable adjustments to work law refer only to those with disabilities.

Balancing multiple roles and lack of personal time.

Young carers often feel guilty about taking time for themselves, which can create tension between their need for personal space and their caregiving responsibilities. This struggle to balance their caregiving responsibilities with their own needs, including for education, work, and social life, can lead to role conflict and a sense of being overwhelmed. Young carers may integrate their caregiving role into their identity, which can have long-term implications for their self-esteem and the way they view their future. This can restrict young carers' ability to envision and plan for their future, particularly in terms of education and career aspirations. Results from the Carers Census in Scotland show that over 60% of young carers feel their life balance is negatively impacted because of their role as a young carer.

Stigma, lack of recognition and support.

There is a general lack of awareness and understanding of young carers' situations among healthcare professionals, educators, and the public, leading to inadequate support and recognition of their needs. In addition, there often is also a lack of awareness and understanding of young carers' situations by those around them which can lead to feelings of invisibility and stigmatization.

3.2. What are the challenges faced by organisations that support young carers?

Survey responses and discussions at the focus group highlighted that the predominant service delivery model for young-carers is in-person support. Organizations offer a comprehensive range of services including financial assistance, respite care, health maintenance support, emergency planning, mental health services, social connection facilitation, specialized care coordination, recreational activity suggestions, caregiving assistance, and emotional support.

The support available to young carers in Scotland varies by region, depending on funding and support bodies present in each area. Regional organizations typically support between 100-300 young carers, but the range is wide with larger organizations supporting over 700 young carers.

Discussion highlighted the following challenges faced by organisations that support young carers that could be helped by tech solutions:

Administrative and documentation hurdles.

Organisations frequently encounter difficulties with the current administrative systems. For instance, paper-based statements for young carers are time-consuming to complete. Transitioning to an online system with real-time updates would significantly improve efficiency. Additionally, digitalising care plans and social activities could streamline administrative tasks.

Challenges in social event coordination.

Coordinating social events for young carers is often cumbersome. Implementing a dedicated app for managing RSPVs and tracking upcoming activities would improve efficiency and ensure better communication about events.

Communication and support networks.

Maintaining effective communication between young carers, their families, and support organizations can be challenging. Technology can play a pivotal role in bridging these gaps by offering platforms for instant messaging, video conferencing, and forums for peer support. These platforms would enable young carers to connect with their support networks more easily, share experiences, and seek advice in real time. Additionally, regular virtual meetings and webinars could be organized to provide ongoing training and emotional support, fostering a sense of community and belonging among young carers.

Access to resources and information. According to survey participants (Figure 2), young carers need timely access to resources and information to manage their caregiving responsibilities effectively. Technological improvements could significantly enhance this access. A centralized online portal or mobile app could serve as a comprehensive hub, providing educational materials, health information, and links to relevant services. Interactive features, such as chatbots and FAQs, could offer immediate assistance and guidance. Additionally, personalized content tailored to individual needs and preferences would enrich the learning experience, ensuring young carers have the necessary tools and knowledge to fulfil their roles more effectively.

Resource constraints.

A bottleneck in human resources, limited staff numbers, and time are significantly hindering the implementation of technological solutions (Figure 1). This suggests that organizations are struggling to allocate sufficient resources to explore, evaluate, and integrate new technologies, despite recognizing their potential benefits.

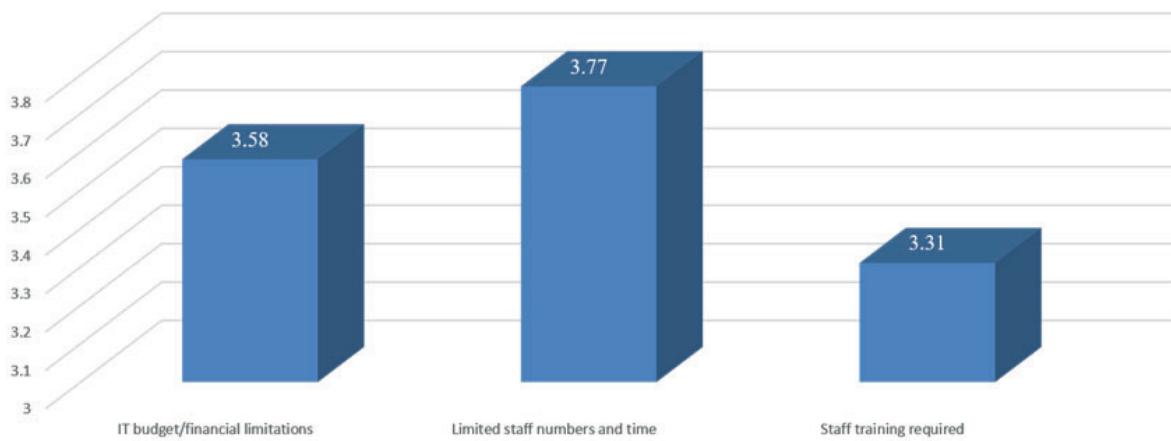


Figure 1. Challenges hindering technology implementation (from 1 to 5).

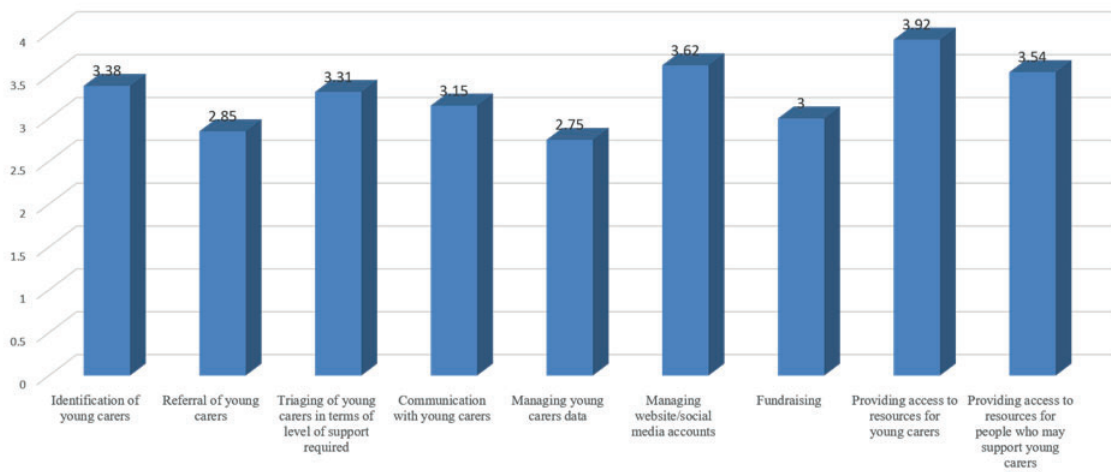


Figure 2. Areas that could benefit from improved technology solutions (rated from 1 to 5).

4. Can technology help?

Some of the challenges faced by young carers can be met with the help of technology. To explore this, we conducted a comprehensive focus group with participants actively involved in supporting young carers. This in-depth discussion allowed us to examine how technology might address these challenges effectively. The insights gathered were categorized into strengths, weaknesses, opportunities, and threats related to implementing technology as a solution. These categories, detailed in Figure 3, provide a structured framework for understanding the potential impact of technological integration. They highlight both the benefits and limitations of technology in enhancing support services for young carers, offering valuable guidance for future improvements and innovations in this critical area.

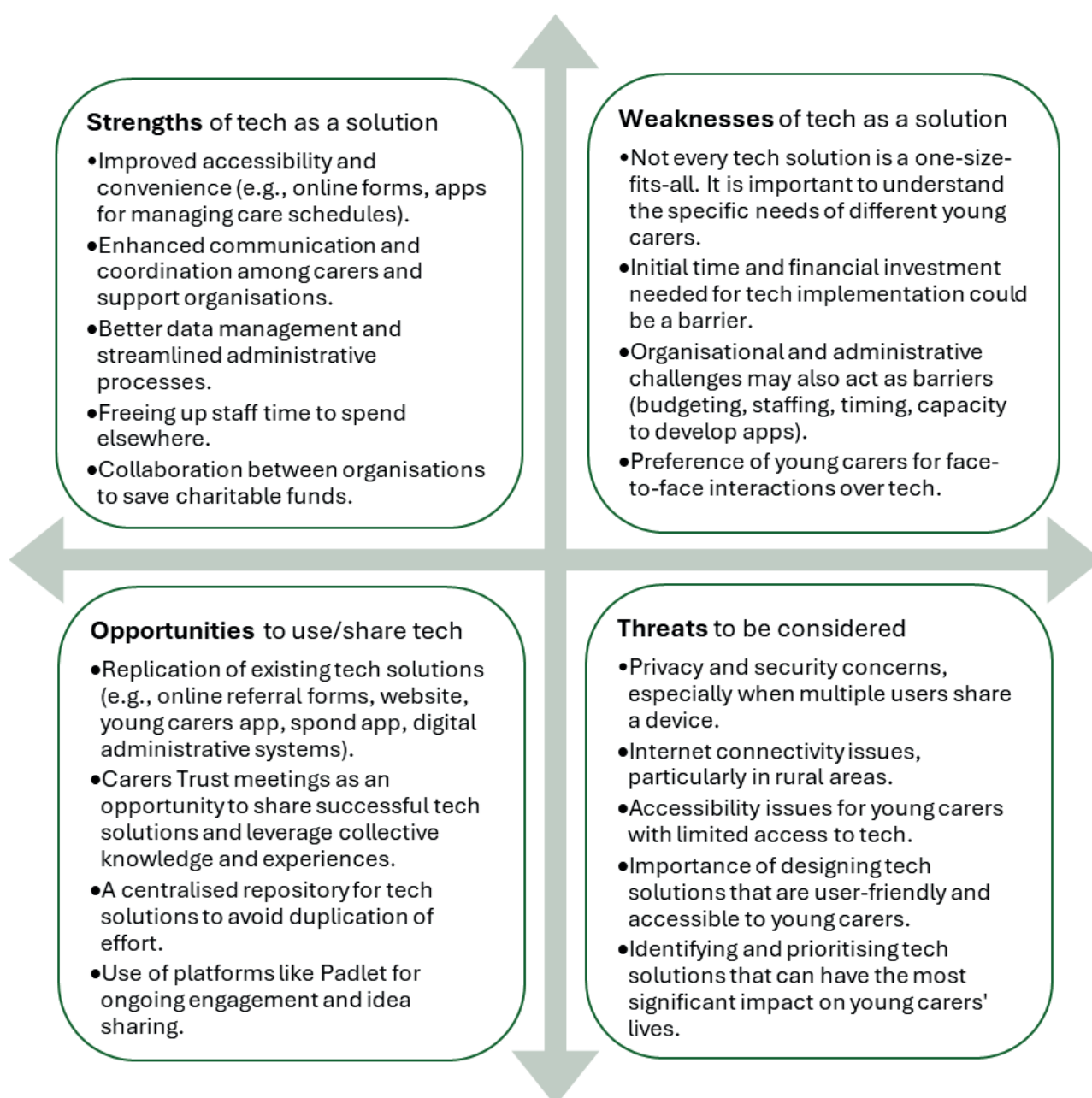


Figure 3. Strengths, weaknesses, opportunities and threats analysis of tech solutions

4.1. Existing tech solutions

Currently available support to help young carers through technology include:

- Online platforms and apps
- Virtual support groups and webinars
- Carers passports and digital tools
- Creative and recreational projects
- Computers and smart phone donations
- Counselling and mental health support

Survey responses also showed that over 90% of organizations utilize social media as a primary channel for connecting with young carers. A significant majority (67%) of these organizations maintain a daily social media presence, with the remaining 33% providing weekly updates.

However, it should be noted that not all these solutions are available equally to all young carers across Scotland and UK. For example, many organisations struggle to keep their websites and online platforms up to date and lack the staff or experience to organise virtual recreational meetups or activities. Moreover, remote areas of Scotland still have very poor access to internet and not all households have access to personal physical devices such as phones or iPads. Our work focussed on identifying the different challenges faced across different parts of Scotland and the potential solutions that could be implemented to overcome these.

Discussion highlighted that details of tech solutions already implemented should be shared to assist other organizations with similar challenges. To that end, we have set out in Table 1 a high-level summary of existing tech solutions that we have been made aware of throughout this project, alongside details of the organization(s) that have implemented them where known.

Table 1. Existing tech solutions to support organisations working with young carers

Challenge	Tech solution	Implemented by
Administrative burden of the referral process	Microsoft Forms online referral form	Dumfries Young Carers (and others)
Communicating details of group events with young carers	Spond app	Fife Young Carers
Facilitating communication and peer support among young carers	WhatsApp group	Various
Completing Young Carers Statements	Young Carers app	Argyll and Bute
Counselling	Online counselling	Islands
Educational difficulties due to missed classes/lectures	Recording of lecturers	School/University dependent
Employability prospects for young carers	Gaming socials to raise interest and awareness of career prospects	Fife Young Carers
Managing caring responsibilities	Jointly app	Carers UK
Usefulness of website	New website	Fife Young Carers

4.2. Suggestions from organizations

Suggestions from organizations on tech developments that would be beneficial for future implementation centered around four main themes:

1. **Engagement and Connection.** Participants reported that digital solutions could provide the ability to expand on existing support, improve engagement (both in person and virtually) and create opportunities for peer-to-peer support.

“More opportunities for YC to engage digitally”

“Apps to allow direct contact/support”

“They want to come together in person [...] make more use of other social media (to make that happen)”

2. **Young carer friendly.** Participants felt that existing digital technologies were adult centric and not specific to the needs of young carers, resulting in poor engagement and the need to rely almost solely on face-to-face contact as the main support means.

“Need to improve website and create a better dedicated YC section”

“We could do better to make data available for YC in a space that feels theirs”

“Our young carers do not really want to connect online on our existing platform”

3. **Moving with the times.** Almost all responses mentioned the need to communicate in the most up-to-date manner, reporting that existing websites were outdated and did not communicate with young carers in a manner which best met their needs.

“We feel that social media platforms may have more impact than web site alone”

“We need to get our website improved”

4. **Efficiency.** Along with meeting the needs of young carers, participants also reported that there was an opportunity to improve organisational efficacy. It was noted that steps had been taken by organisations to implement changes with a view to streamlining tasks (namely administrative) in the interests of increasing time spent directly supporting young carers.

“We also try to use IT solutions to improve organisational efficiency, eg mileage recording app”

It was acknowledged by participants that any potential digital solutions are required to be compliant with company policy and this can restrict the implementation of solutions which participants felt would benefit both their organisations and the young carers themselves.

In the context of website development, Figure 4 shows that organisations are encouraged to focus on creating and using online forms and submission features. Additionally, it's recommended that organisations work on integrating and enhancing their social media integration features.

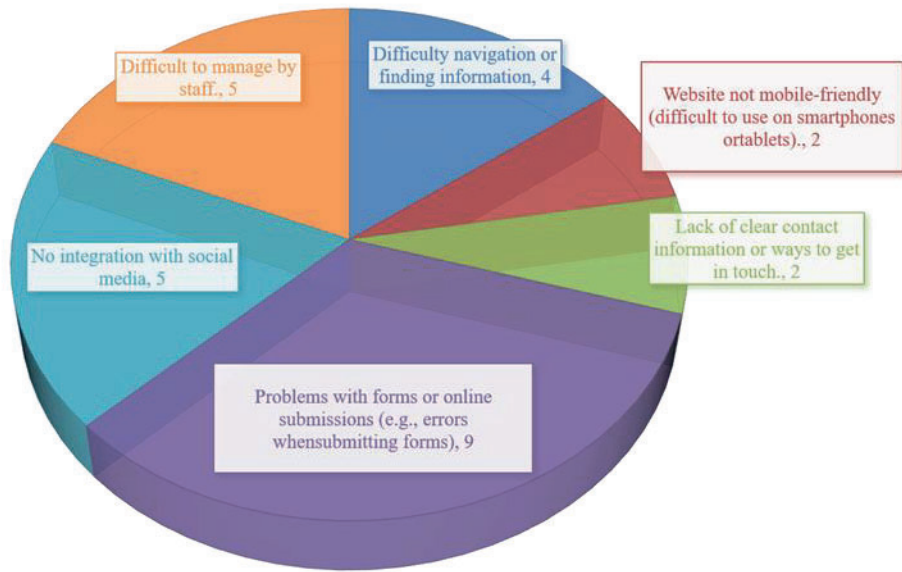


Figure 4. Areas the organization want to address on their website.

5. Recommendations and next steps

Considering the above, we can identify both straightforward, easily implementable steps and more complex solutions that require high-level engagement from government and education sectors. The latter will likely involve a longer-term commitment for successful implementation. Based on the context, survey, and focus group recommendations, here is a structured approach to developing tech solutions, categorised into quick wins and long-term projects:

1. Quick Wins:

- a. **Adopting a Data Management System** – It is recommended that organisations adopt a data management system rather than building one from scratch. Systems such as CharityLog cloud offer robust features that can significantly improve data management efficiency. These platforms provide centralised solutions for managing various data types, including funder/donor and referral information, thereby reducing reliance on manual systems, and improving data consistency. Additionally, these solutions include training and support, facilitating a smoother transition and ensuring best practices are followed.
- b. **Central Repository** – Implementing a centralised repository with readily available technological solutions and resources for organisations and young carers to access and share. This would reduce duplication of efforts and provide quickly accessible, up-to-date resources. Alongside this, STA should develop 'best practice tech solutions' to serve as a roadmap for all organizations. This strategy will minimize duplicated efforts and enhance technology integration across different challenges, ensuring adherence to important regulations like GDPR and child protection standards. By adopting these best practices, organizations can streamline their processes, improve their operations, and provide better support to young carers and relevant stakeholders.

2. Long-Term Projects:

- a. **Digitalisation of Young Carers Card** – Transforming physical identification cards for young carers into digital formats. Digital cards can be easily verified by scanning a QR code or through an app, making it easier for young carers to be recognised and supported in various settings, such as schools and healthcare facilities.
- b. **Digitalisation of Young Carers Assessment** – Moving the assessment process for young carers to a single, centralised digital platform used by all organisations. This would streamline data collection, improve accessibility, and facilitate better tracking of assessments and support needs across different organisations.
- c. **Core Digital Platform** – Developing a single app or website that addresses all the challenges outlined, reducing the need to manage multiple apps and alleviating the burden on staff. A core digital platform, which could be adopted by each organisation, would provide more streamlined and consistent information for young carers. While the benefits of core systems and resource sharing were widely discussed, potential barriers and unintended consequences were not fully explored. Considerations such as irrelevant information for some organisations and their contexts need to be addressed. It was suggested that features from WhatsApp Communities could be incorporated into this application, excluding the requirement to share one's mobile number to sign up.

Further, it is crucial the following practicalities are considered when developing tech solutions:

- **Simplicity and streamlining** - Organization resources and time are under pressure, so any solution must help streamline processes and be simple to implement. Solutions requiring significant costs and training will likely lead to resistance to change and deter uptake.
- **Costing and funding** - Many organizations are facing budget freezes and/or cuts; therefore, funds for tech development are limited. Therefore, any solutions must be affordable and/or offer long term financial savings.
- **Compliance with legislation** - Careful consideration of how technological solutions and legislation are required (e.g., GDPR, child protection) when working with young individuals. For example, many organizations cannot have social media due to age restrictions and potential risks. Young carers below the age of 13 cannot register with certain forms of social media like Facebook. Similarly, platforms such as WhatsApp require personal data sharing. Technological solutions should comply with data minimization and relevant child protection policies. STA may be able to assist in moving these policies and regulations forward to allow the benefits of social media platforms to be realized.
- **Resource Sharing** – Thought needs to be given to the practicalities of resource sharing and consideration of how to promote interest and ensure uptake among different organizations.

We trust this report will be helpful in assisting STA and the organisations that support young carers to improve the lives of young carers by empowering them through tech.