



**Submission on the Data Protection
Commission Regulatory Strategy**

June 2021

Introduction

Sage Advocacy is a support and advocacy service for vulnerable adults, older people and healthcare patients. Every year we receive a large number of referrals for advocacy and requests for information and support issues.

Through our advocacy case work, Sage Advocacy is very aware of issues regarding the use, collection and sharing of data and our observations are driven by our experience.

Similarly, in the exercise of our functions, Sage Advocacy has encountered situations in which relatives of clients have tried to seek access to data belonging to their relative, and/or data submitted by family members related to the client.

Overview of Strategic Goals

The Commission lists 5 Strategic Goals;

1. Regulate consistently and effectively,
2. Safeguard Individuals and promote data protection awareness,
3. Prioritise the protection of children and other vulnerable groups,
4. Bring clarity to stakeholders,
5. Support organisations and drive compliance.

Sage Advocacy has provided feedback under two goals, specifically

- a) Safeguard Individuals and promote data protection awareness, and,
- b) Prioritise the protection of children and other vulnerable groups

Safeguard Individuals and promote data protection awareness

Generally, there is a need to raise data protection awareness, particularly among adults who are at risk of abuse, families and professionals who may be working with older people or people with disabilities.

This will include a variety of approaches and methods to deliver information to support such as easy to read and Plain English.

Through our advocacy work, Sage Advocacy has identified that that there is considerable uncertainty and lack of clarity among individual professionals and within statutory, voluntary and business organisations on what, if any, information can be shared between individuals and organisations where there

are concerns of abuse, neglect and/ or exploitation of a vulnerable adult. This lack of clarity is, by itself, creating and amplifying risk.

In many instances, the sharing of information can be vital in helping to prevent or stop abuse of a vulnerable adult. Lack of clarity arises particularly in cases where a) The vulnerable adult lacks capacity to give consent for sharing of information. b) There is a need to share concerns/ information between agencies in order to prevent/ stop abuse.

Most recently, through our case work Sage Advocacy has become aware of specific concerns relating to sex-offenders and nursing homes. The issues related to a lack guidance around the sharing of relevant (high risk) information between an Garda Síochána and private nursing homes providers and the lack of guidance around an Garda Síochána's duty to notify nursing homes providers of known sex offenders in the community who become residents of nursing homes.

While there are clear reporting guidelines in place regarding reporting sexual abuse when it allegedly occurs in a care setting to HIQA, HSE Safeguarding Vulnerable Adults Teams and an Garda Síochána, there are no similar guidelines regarding the sharing of information when;

- An alleged offender is moving from the community to a nursing home setting,
- An alleged offender is moving between care settings,
- An alleged offender is moving from a nursing home setting to an acute hospital setting.

In practice, this lack of clarity and absence of guidelines relating to relevant information has resulted in serious matters giving rise to safeguarding concerns and the potential and alleged abuse of vulnerable adults.

In this context, it is welcome that the DPC has included an action to take account of "how data protection impacts vulnerable groups and engaging with advocacy groups to communicate this appropriately" and that it is proposed that codes of practice will be developed in this regard.

The experience of Sage Advocacy is that the sharing of personal data may be appropriate where it is in the public interest to do so and where the safeguarding of vulnerable adults is at hand. Section 60 of the 2018 Act provides that the rights of controllers and data subjects may be restricted in the 'public interest' but needs regulations to provide for this.

It is important that the DPC include a specific action relating to data sharing in this section.

Additionally, Sage Advocacy is aware of circumstances where data sharing in relation to previously convicted sex offenders has resulted in a person being unable to find appropriate accommodation or having their movement restricted.

A data sharing protocol to protect a person's right to liberty and freedom of movement is required as well as protecting the rights of others.

Prioritise the protection of children and other vulnerable groups

In our submission to the Data Protection Commission (DPC) in February 2020¹ we noted that the outcomes stated that "children are specifically protected" and that there was no mention of vulnerable adults. Therefore, it is welcome that the protection of children and other vulnerable groups is included.

In our submission of February 2020, we suggested that a separate section specifically focusing on vulnerable adults could be included and that linking children and vulnerable adults suggested that both issues are similar and this is not the case. Sage Advocacy remains concerned that there is a strategic goal included in this strategy that conflates children and vulnerable adults.

We suggest that distinct goals are set for both groups, however at a minimum that the goal would be renamed "prioritise the protection of those who may be vulnerable" and to include children, older people and people with disabilities etc. within the "desired outcome" definition.

With regard to the specific actions involved, Sage Advocacy welcomes the commitment to developing and promoting codes of conduct on the processing of the personal data of vulnerable adults. Sage Advocacy had called for this to be included in our earlier submission.

We also welcome the commitment to consult with stakeholder agencies as we believe that it is by using the experiences of independent support and advocacy services, such as Sage Advocacy, in developing guidance for individuals and organisations based on the experience of practitioners on the ground that robust and practical codes of practice will be developed.

Actions relating to "conducting detailed research on how data protection law applies to children" and "defining the specific protections required to safeguard the rights of children in the protection of their personal data" are very important and specific provision on both of these matters should also be provided for vulnerable adults. Vulnerable adults include not only those whose decision-making capacity is in question but also those who may be at risk due to, for example, mental health difficulties.

Although it is welcome that there is a statement that "obtaining information is not impeded by language, capacity, financial or other barriers", it is

¹ Submission to Data Protection Commission on Regulatory Strategy 2020-2025

disappointing that there is no mention of the Assisted Decision-Making (Capacity) Act, 2015 and the need to link data sharing decisions with decision-making capacity and in assessing data protection concerns. Agencies and organisation should address issues of consent in relation to vulnerable adults.

In many instances, the sharing of information can be vital in helping to prevent or stop abuse of a vulnerable adult. Lack of clarity arises particularly in cases where an individual lacks capacity to give consent for sharing of information or, as is mentioned earlier, there is a need to share concerns/information between agencies in order to prevent/stop abuse.

Conclusion

Sage Advocacy believes that there are some very welcome provisions included in this strategy and welcome the opportunity to make a submission.

It is critically important that clear communication on data protection to all of those who may benefit or be protected takes place, including clarity on when data may be shared in the public interest.

Additionally, the protection of vulnerable adults is welcome, however care must be taken not to conflate children and adults in relation to safeguarding.

Finally, Sage Advocacy welcomes the inclusion of a commitment to consult with stakeholder agencies and look forward to future engagement with the Commission.

For further details contact Sage Advocacy

Phone: (01) 536 7330

Email: info@sageadvocacy.ie

Website: www.sageadvocacy.ie