

## **Submission to Data Protection Commission on Regulatory Strategy 2020-2025**

**Date: 10<sup>th</sup> February 2020 (With apologies for breaching the deadline)**

Sage Advocacy is a support and advocacy service for vulnerable adults, older people and healthcare patients. In 2019 it received 1,570 referrals for advocacy and 3,964 Information & Support cases were recorded. Sage Advocacy works closely with Safeguarding Ireland which promotes the rights of vulnerable adults.

Sage Advocacy welcomes the **Public Consultation on the DPC's Regulatory Strategy 2020-2025- Consultation Round 1 of 2: Target Outcomes.**

The work of Sage Advocacy is challenging and involves focusing on empowerment as well as safeguarding of vulnerable clients. Since the service started in 2014 we have noted many situations in which relatives of vulnerable clients have tried to seek access to data which they believe we might hold on them to find out what information may have been provided about them in the context of fears being expressed about possible involvement of family members in abusive or criminal behaviour. Arising from these and related experiences we have formed the view that there is a need to support and protect vulnerable clients by including in data protection legislation a specific defence against liability, where there is a reasonable belief that there is a safeguarding issue.

**Consultation Question 1. Is there any other distinct outcome that the DPC should include and why? How would that additional outcome fit with the existing target outcomes?**

Outcome no. 5 on page 12 states that "*Children are specifically protected*". Under this specific outcome, on page 23, it states that "*we are especially passionate about safeguarding the rights of vulnerable people and most particularly the rights of children*". However, the specific activities outlined under this outcome relate

specifically to children **with no further mention of vulnerable adults**. Sage Advocacy is fully in agreement with the need to specifically protect children but are concerned that there should be an equal concern to protect vulnerable adults. We would suggest a separate section specifically focusing on vulnerable adults. Linking children and vulnerable adults suggests that both issues are similar and this is not the case. In any new section on vulnerable adults, we propose the following activities be undertaken by the DPC.

1. Through consultation with stakeholder agencies, developing and promoting codes of conduct on the processing of the personal data of vulnerable adults. These codes of conduct should address issues of consent in relation to vulnerable adults.
2. Defining the specific protections required to safeguard the rights of vulnerable adults in the protection of their personal data, and providing guidance for individuals and organisations;
3. Using the experiences of independent support and advocacy services, such as Sage Advocacy, in developing guidance for individuals and organisations;
4. Undertaking research on how data protection law applies to vulnerable adults, both internally and through research partnerships.
5. Linking data sharing decisions with decision-making capacity and the Assisted Decision-Making (Capacity) Act, 2015. in assessing data protection concerns.

The inclusion of activities specifically related to vulnerable adults would play a significant part in safeguarding them from abuse and, in addition, provide clarity to agencies dealing with vulnerable adults on data collection and sharing in circumstances where people may be suffering abuse, neglect and/or exploitation. Inclusion of the above would support the other four outcomes.

- Outcome 1- Data Protection rights and obligations are regulated consistently.
- Outcome 2- There is clarity and certainty in how data protection law is applied.
- Outcome 3- Organisations operate and innovated in an accountable compliant, ethical and fair way in their processing of personal data.

In respect of Outcome 2 Sage Advocacy's experience is that there a need for both clarity and certainty among individuals and agencies in relation to data protection law and dealing with cases of suspected abuse, neglect and/or exploitation of vulnerable people.

**Outcome 2. There is clarity and certainty in how data protection law is applied**  
**Consultation Question 3. What are the most critical gaps in legal clarity and certainty that may be hindering organisations in being compliant or that may be negatively impacting the rights of individuals?**

The experience of Sage Advocacy is 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. 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.

**Consultation Question 4. *Which of the DPC's activities have the greatest effect on achieving the target outcome on legal clarity and certainty?***

- Providing guidance on how the law supports individuals in controlling use of their personal data, to ensure that they are clear in how to exercise their data protection rights;
- Using a variety of approaches and methods to deliver information to support those who are the most vulnerable;
- Providing scenarios and case studies to illustrate guidance on how data protection law should be applied both in general and in specific contexts.
- Prioritising information based on issues / areas of non-compliance or that could have the most impact in improving protections without in any way diminishing the potential for innovation in the delivery of services.
- Assessing how an inquiry into a potential infringement might clarify how specific obligations apply in specific contexts in the process of planning an inquiry.

**Outcome 4. *As many people as possible understand and have control over how their personal data is used.***

Sage Advocacy agrees with this outcome and, again, stresses the need to reach those who are, because of their vulnerabilities, particularly hard to reach.

**Consultation Question 8. *How can we set the right balance between our work on individual complaints and our work on issues that can affect millions of people, so that we have the greatest impact for as many people as possible?***

Clear guidance using scenarios and case studies regarding individual issues could, in time, assist in reducing the level of work on individual complaints. Clarity regarding organisational responsibilities for data protection and consistency in applying the legislation is critical for success.

**The rights of vulnerable adults regarding use of their data must be specifically promoted, protected and defended.**

