

Sharing Information about patients and service users with the voluntary sector

1. Voluntary and Community Sector (VCS) organisations often work with the most disadvantaged communities and can make an invaluable contribution to integrated care. Provided that the following guidance is followed there should be no problem in sharing relevant information with, or receiving it from, VCS organisations. There is every reason why health and care organisations should support these increasingly important partners in understanding and meeting information governance requirements where necessary.

The Duty of Care and the Duty to Share

2. All those involved in care have a common law duty of care (and in many cases a statutory duty to share information for care¹). Dame Fiona Caldicott's second information governance review also introduced a new Caldicott Principle emphasising that sharing information can be as important as protecting confidentiality. This requires that relevant information about individuals is shared with all those involved in care, subject to confidentiality and consent requirements, where this may result in improved outcomes or experience for those individuals. Health and care organisations, both providers and commissioners, should proactively seek out VCS partners as a component of integrated care. The best source of support for linking with the voluntary sector will often be the local council for voluntary services (CVS).
3. It is essential that information requirements are fully understood by all parties and these may vary widely between different services. The information that a particular VCS partner organisation needs in order to contribute effectively must be determined locally. Information sharing agreements, if kept simple and focussed, can be an invaluable mechanism for setting out information requirements, the legal basis for sharing and the required information governance standards that must be met.

The Duty of Confidentiality

4. Information about patients and service users must be treated respectfully, not shared with those who do not 'need to know', and must be held in and shared through secure systems and processes. As mentioned above it is essential that information requirements are fully understood so that sharing is neither excessive nor overly restricted and that information governance arrangements ensure that information is held safely and securely.
5. When an individual objects to any proposed sharing of information about them, whether for care or other purposes, their wishes should be respected unless there are exceptional circumstances². The consequences of not sharing for care should be carefully explained but if an individual has the capacity to make this decision then it is their choice as the legal basis for sharing for care is almost invariably consent. Within clinical care settings this consent is usually implied as a consequence of people presenting for care but it is important that no-one is surprised or upset by information sharing that they didn't anticipate and weren't informed about. When planning to share information more broadly than the clinical care settings, e.g. with a VCS organisation, organisations need to ensure that the patient or service user understands what is proposed and has indicated that they are happy for it to happen.

¹ The Health and Social Care (Safety and Quality) Act 2015

² In the absence of consent, sharing may still be justified where there is a statutory basis or a strong public interest reason - guidance is available from the IGA [website](#)

6. This consent should be captured in the care record by the body that is planning to share information. A signed consent form, countersigned by the member of staff who sought the consent would be a good way of achieving this.

Sharing information for purposes other than care

7. There needs to be a clear basis in law for all sharing of information. There are statutory ways of authorising information sharing for specific purposes, and some purposes are so important that confidentiality has to be set aside. This can be a complex area and the key requirement for VCS organisations and their staff is that their policies, procedures and training ensure that they do not disclose information unlawfully. Health and care organisations who may have more experience with these issues and greater resources might helpfully advise partner organisations on the content of policies, procedures, confidentiality codes and training and extend access to their Caldicott Guardian or Information Governance lead to support decisions about sharing information.

Demonstrating Good Information Governance

8. Health and care organisations must provide assurance about the way that they manage information about patients and service users by completing the on-line Information Governance Toolkit³ which contains a view for voluntary sector organisations to complete. The key requirements that need to be in place within a VCS organisation are identified in the accompanying text box.

- People should be told what organisations are doing with their information and who it will be shared with and what their rights are, e.g. to object and to have access to what information is held.
- Responsibility for Information Governance should be assigned to an appropriate member of staff.
- All contracts (staff, contractor and third party) must contain clauses that clearly identify information governance responsibilities.
- All staff members must be provided with appropriate training on information governance requirements.
- There should be a confidentiality code of conduct that provides staff with clear guidance on the disclosure of personal information.
- Unauthorised access to the premises, equipment, records and other assets is prevented.
- All portable devices - e.g. memory sticks and laptops - used to store personal information are encrypted.
- There are documented retention periods for information and people's information is only held for as long as necessary.

9. Staff and volunteers should be supported in following good information governance practice and VCS organisations may need support to evidence that they and their staff know that they understand what is required. An information governance lead from a larger health or care organisation may again provide small partner VCS organisations with support, if his/her employing organisation agrees, in order to ensure that data is managed securely and confidentially.

10. Organisations that disclose information about patients/service users to others must seek assurance that they are not putting that information at risk. An honest and satisfactory IG Toolkit performance assessment can provide the required assurance.

³ The IGT can be found at <https://www.igt.hscic.gov.uk/>