



National Long Term Survivors Group Policy on Confidentiality

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A. Purpose and Scope

1. National Long Term Survivors Group (hereafter NLTSG) recognises the need for strict confidentiality, this being all the more relevant in relation to people living five years or longer with HIV infection and AIDS.
2. NLTSG recognises that the consequences of confidentiality being broken can be disastrous and requires all members, staff and volunteers to adhere to this policy.
3. As an employer of paid and unpaid staff, NLTSG has a responsibility to ensure that information about staff and volunteers is held and used properly.
4. As an organisation, NLTSG is constantly dealing with internal issues, which are not appropriate for public discussion.
5. It is the right of individuals to judge for themselves what personal information may or may not be disclosed and passed on and to whom. An individual may choose to keep private any personal issues, whether or not a disclosure is damaging to her/him. Generally speaking, personal information should only be passed on with the specific consent of the person concerned.

B. Holding and Use of Information

1. As a general principle, information should be held on a 'need to know' basis. To determine whether someone needs to know a piece of information, we need to ask ourselves questions such as: 'Is there a legal requirement for the person to know?' 'Is the person unable to use or provide a service unless they know?'
2. Any information about members of NLTSG, people who attend the weekend and other support facilities should be stored in as securely as possible and any information held is only accessible to those authorised by the Trustees.
3. A list of all people who receive the information about services will include only information essential to providing this information and is accessible only to the person/s authorised by the Trustees.
4. Names and addresses and phone numbers of volunteers are accessible only to the person/s authorised by the Trustees, as appropriate.
5. People using services or taking part in activities may be asked to give their first name, town and "in" post-code of origin and ethnic identity, for monitoring purposes. It is not intended that this information should be traceable back to any individual nor will it be given to any funding authority under any circumstance. For funding purposes area of residence will only be given.



6. NLTSg must by law keep records of the names and addresses of staff or individuals employed. There are also records of absence, leave and meetings. All records are only available to the Trustees, except as detailed in B.9 below.
7. Information about staff and individuals employed is expected to be shared only directly 'upwards' in the hierarchy, not 'crossways'. For example, a facilitator would formally discuss issues with a Trustee, who would then, with approval, take this up with the chair.
8. Trustee meetings and any sub-committee meetings are not intended to be used for discussion about individual staff, members of NLTSg or service users.
9. Meetings of Trustees and its sub-committees are confidential, although for the time being minutes are made available to members of NLTSg. Minutes are available to NLTSg members who are unable to attend general meetings on written request to the Chair of the Trustees.
10. Information about people using services or taking part in activities may be passed on in circumstances where this is necessary to implement internal disciplinary or grievance procedures. Personal information may be passed on where, if it were not, significant damage would be caused to NLTSg or service users. Such sharing of information may be done only to the extent that is necessary to protect the organisation or people in it.
11. Where it may be helpful to pass on information, permission must be sought from the person concerned. (For example, information about members being passed from one person to another with a need to communicate important information.)
12. The only people who are allowed to speak to the press or mass media on behalf of NLTSg are: the chair of the Trustees or those properly authorised by them.
13. Breach of confidentiality, as defined in policies and procedures, can (but need not) be treated as gross misconduct.

C. Guidance for members

1. Our aim is to provide a safe welcoming environment for everyone that comes to the NLTSg weekends.
2. Information about each person belongs to them and should not be shared without their consent. This includes all aspects of a person's life i.e. HIV status, sexual orientation, lifestyle, personal finances and history.
3. You must be careful if you meet people from the NLTSg weekends in your everyday life. If you approach people in other situations you may cause a breach of their confidentiality about their status.
 - Do not acknowledge them unless they acknowledge you first.
 - Take care not to mention how you know them, or just say they are a friend of a friend.



- Never mention anyone by name or share information about them, especially details that could identify the person.
- What and who you see here remains at the weekend.
- If you exchange contact details with another member, do not pass on their details to anyone else without their permission.

D. Interpretation and Review

1. The Trustees are charged with the interpretation and review of this policy, where there is lack of clarity or dispute. They are also responsible for reviewing the policy annually. It is the duty of organisers and co-ordinators of any event to ensure the policy is advertised and understood.

E. Notes

These notes aim to highlight circumstances which might result in a breach of confidentiality. It is sometimes the case that information, even if it is disguised, about an individual can lead to recognition of that individual. It is helpful to remember that the vast majority of breaches of confidentiality occur from good motives, usually a desire to seek or give support or to improve the organisation's efficiency.

1. Information collected about individuals in the course of work for NLTSG, e.g. at the weekends, in a support group, through publications.
2. Outside of NLTSG in social settings, overt recognition of NLTSG users or members.
3. Discussion of NLTSG business in a social setting.
4. Volunteers or staff being approached for support outside of NLTSG.
5. Volunteers and staff on external training.
6. Discussion about other staff, volunteers or users, whether implied or direct.
7. Individual support and personal discussions being held in an open or general space where others may overhear.
8. Where advice relating to an individual is sought from a supervisor, co-ordinator or support group.
9. Where names and addresses are recorded for one purpose and used for another.
10. Where tasks are delegated, involving passing on information, without clarifying the confidentiality of this information.
11. Concern amongst service users or committee members about a volunteer or member of staff, such concern being shared inappropriately at meetings.
12. Papers, diaries, memos and names and addresses being visible in offices.

