

As HIV moves into a chronic disease – how involved are patients in their own care?

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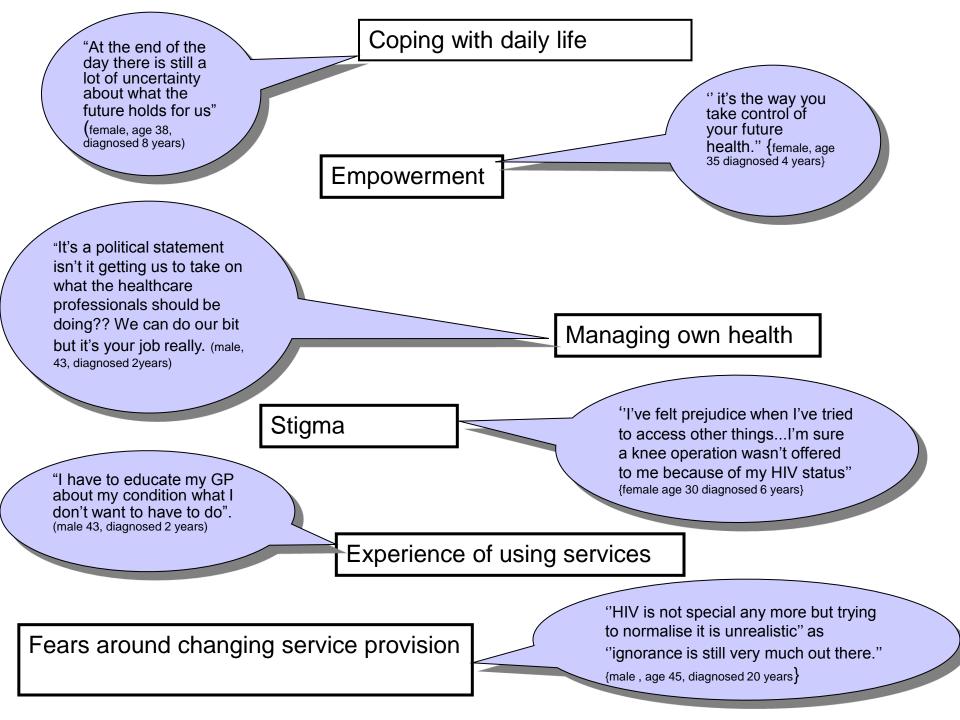
On behalf of the Sussex and Surrey HIV Nurses Network (SSHNN).



Aims of the study:

 To explore the lived experience of people living with HIV who are accessing healthcare services

 To investigate to what extent health needs are being met and peoples' confidence and ability in accessing care and support



Conclusions:

- Some people continue to need regular support and have concerns about current changes to service provision including fear of losing the 'specialism of HIV care'.
- Most participants had experienced stigma socially and in non HIV specialist clinical settings. Specialist HIV services provide protective and reassuring environments.
- Variability of knowledge amongst non HIV HCPs, especially GPs and other specialities was described by participants as a barrier to accessing other services.
- Empowerment meant different things to people but includes self sufficiency in managing own health, knowledge and accessible health advise especially at vulnerable times.
- Peer support and voluntary sector support groups are seen as a valuable resource in terms of building confidence, knowledge and as a source of health related advice.
- Access to psychological support is seen as a priority. Participants felt a need for medical professionals to appreciate that living with HIV has 'ups and downs', is unpredictable and affects all aspects of daily life.