

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

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(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

Coping with daily life

“At the end of the day there is still a lot of uncertainty about what the future holds for us”  
(female, age 38, diagnosed 8 years)

Empowerment

“ it’s the way you take control of your future health.” {female, age 35 diagnosed 4 years}

Managing own health

“It’s a political statement isn’t it getting us to take on what the healthcare professionals should be doing?? We can do our bit but it’s your job really. (male, 43, diagnosed 2years)

Stigma

“I’ve felt prejudice when I’ve tried to access other things...I’m sure a knee operation wasn’t offered to me because of my HIV status”  
{female age 30 diagnosed 6 years}

Experience of using services

“I have to educate my GP about my condition what I don’t want to have to do”.  
(male 43, diagnosed 2 years)

Fears around changing service provision

“HIV is not special any more but trying to normalise it is unrealistic” as “ignorance is still very much out there.”  
{male , age 45, diagnosed 20 years}

# 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 advice 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.