The future of HIV services in England

Shaping the response to changing needs

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Exploring change

› **Changing societies, communities, knowledge, science and technology**
  › What does this mean for HIV services?

› **Changing needs of people living with HIV**
  › Are services prepared for larger numbers of people with HIV, with needs that are different from those in the past?

› **Changing roles and responsibilities**
  › The health reforms of 2012 have divided up responsibilities for HIV and for sexual health between NHS England, local authorities and clinical commissioning groups (CCGs).
  › How are HIV services managing this complex arrangement?
  › Can they keep pace with changes that will be needed in the future, and with new technologies and interventions?

› **Changing policy environment**
  › Health policy is encouraging integration and new care models to ensure sustainable services.
  › How will these broader changes affect HIV services, and what opportunities do they create?
More people with differing needs

More people than ever before living with HIV in the UK.
• Ongoing infection
• Better treatment
• Fewer deaths
• Life expectancy rising
• Mental health problems
• Quality of life less good

More people getting older
• Co-morbidities
• Polypharmacy
• Complex care needs

Figure 2: Number of people accessing HIV specialist care, United Kingdom, 2006–2015, by age

Source: Kirwan et al 2016
Commissioning

The Health Reforms of 2012 have divided responsibilities across the HIV pathway and for sexual health between

- **NHS England**
- **Local authorities**
- **Clinical commissioning groups (CCGs).**
About the project

› June 2016 to April 2017
› Interviews with 104 people
  › Key stakeholders
  › Four case study sites
  › People living with HIV
  › Providers and commissioner bodies in Scotland
› Group discussions
  › Five focus groups (n=33)
  › Two workshops with stakeholders (n=45)
› Thematic analysis and write up
› External review
› External advisory Board

Figure B1 Overview of approach and methods

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<th>STAGES</th>
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<th>iii) Future scenarios</th>
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<td>i) Information collection and analysis</td>
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<td>ii) How we got to where we are now</td>
<td>ii) Information collection and analysis</td>
<td>ii) Navigating towards the preferred and avoiding the worst</td>
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<td>iii) Future scenarios</td>
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<td>iii) What needs to change to achieve this?</td>
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<td>Literature review</td>
<td>Literature and data review</td>
<td>Key stakeholder workshops</td>
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<td>Expert advice</td>
<td>Key stakeholder engagement</td>
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Our Findings

Attitudes and understanding towards HIV
- Stigma remains huge challenge and undermines progress across the pathway
- Diversity of people, communities and geography in relation to HIV means tailored responses crucial
- Out of date information about HIV

Prevention
- Different populations, different needs, different approaches
- Combination prevention approaches
- Primary prevention lagging behind secondary prevention
- Lack of strategic prevention planning

System management and leadership
- Hard to find consistent leadership across the whole system
- Tension between “Central” and “Local”
- Accountability complex and dispersed post 2012 reforms
Our Findings

Involvement of people living with HIV
› Consultation happens although many people do not have time to engage and hard in rural areas.
› Each organisation involves people with HIV in their “bit” of the picture, without anyone ensuring that people have influence over the whole picture.
› Taking notice, acting upon and feeding back to people with HIV much harder to find.
› There is suspicion about the reasons for change from service providers and users.

Testing and entry into care
› Wide inequalities in late diagnosis with major prognostic implications
› Broaden testing initiatives

Ongoing treatment and care
› HIV clinical care highly rated.
› Peer support and social care services seen as pivotal for wellbeing
› Management of comorbidities complex and inconsistent
› Primary care: small numbers, variable interest, local champions

Interfaces with other services
› Reduced specialist visits may lead to gaps in care
› HIV inadequately included in long term condition strategies locally or nationally
Our Findings

Quality of life really matters:
› People living with HIV reinforced the importance of quality of life as well as clinical and virological outcomes as a key objective for future HIV services.
› People placed a high value on social, psychological and emotional wellbeing, coupled with effective medication to manage the clinical aspects of HIV

System structure:
› No one we spoke to, at any level or in any part of the system, thought that the distribution of responsibilities for HIV since the 2012 reforms was right.

Reorganisation:
› No one felt that the distraction of energy and time of further reorganisation was the best approach, rather seeking ways of making the current, imperfect system work better.

Maintain excellence
› The need to protect and build on the excellent UK track record in clinical outcomes, data and patient satisfaction were repeatedly highlighted.

Beware losses in cost cutting
› Anxiety that current severe financial pressures risk ‘throwing the baby out with the bath water’.
Recommendations for local action

Create leadership for the system: Directors of Public Health and Lead HIV Clinicians should work together to engage all key stakeholders, and in for planning and developing services across the HIV pathway, including quality of life and appropriate social support.

Formulate a single, overarching local HIV plan: establish shared understanding of how roles fit together, governance across these roles and relationships and ways of working that connect the currently fragmented system. Local HIV plans should nest within health and wellbeing strategies and STP processes.

Build relationships with other services for people with other long term conditions Local HIV services to support common approaches and enable mutual learning.

Test and develop future models for long-term HIV care: Tailor these to be locally appropriate, reflecting differing needs and circumstances.
Recommendations for national action

**Department of Health:** Ensure stewardship for the system, including clarity about roles and responsibilities, robust mechanisms of accountability and monitoring together with expectations of progress. Reflect the reality of HIV in today’s world through an update to the “Sexual Health Framework”, supporting a strategic direction for local action.

**NHS England:** Work to develop HIV service models that meet current and future needs and optimise outcomes and that “fit” with services commissioned by others. Review and assess commissioning strategies for HIV specific and generic support services. Ensure HIV services are fully engaged in the wider discussions and direction of travel for LTCs. Work with partners to deliver national PrEP trial and post trial implementation.

**Public Health England:** Deliver national and local data and guidance to inform actions; Provide leadership to prioritise and join up prevention work streams; expand HIV related indicators, Further develop relationships between PHE centres and HIV service providers and commissioners. Take action to tackle the current variation in rates of late diagnosis

**Health Education England:** Engage with HIV services through regional offices to ensure an appropriate workforce; ensure workforce implications, development needs and opportunities for innovation are identified and reflected in commissioning decisions
In Conclusion

Clinical HIV care in the UK remains world leading, yet risks to future quality of care are real
› Risks for the future from a lack of planning coupled with financial pressures across the health economy
› 2012 reforms make the future models of shared care, and introducing coordinated change, more difficult

Local plans and system leadership are critical if today’s “system” is to work
› Inclusive and across NHS and local authority responsibilities
› Along whole pathway of prevention, treatment and care
› Care partnerships that including focus on quality of life, peer support and social care.
› Include HIV within long term condition plans
› Nested within STP and HWB strategies

National bodies have keys roles to play
› Strategic direction and accountability
› Support for changes (e.g. new care models) and continuing priorities (e.g. stigma)
Thank you

MAC AIDS Fund
UK CAB members Rob, Mel and Jane
Alison Jury for administrative support
Everyone who was interviewed or was part of our focus group discussions
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Workshop participants
External reviewers of the report
All the King’s Fund staff who supported the project and the project team
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## Recommendations for National Bodies

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<th>NHS England</th>
<th>Public Health England</th>
<th>Health Education England</th>
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<td>• Update the 2013 Framework to reflect changing nature of HIV</td>
<td>• Work on HIV service models, ensuring “fit” with services commissioned by others</td>
<td>• Provide the leadership to prioritise and join up prevention work streams</td>
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<td>• Provide overall strategic direction that local plans can reflect</td>
<td>• Support local shared and networked care arrangements</td>
<td>• Deliver national and local data to inform actions</td>
<td>• Ensure workforce implications, development needs, opportunities for innovation are identified and reflected in commissioning decisions</td>
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<td>• Lead national action against stigma</td>
<td>• Work with partners to deliver national PrEP trial and post trial implementation</td>
<td>• Develop and expand HIV related PHOF and other indicators</td>
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<td>• Set expectations and indicators of progress</td>
<td>• Review and assess commissioning strategies for HIV specific and generic support services</td>
<td>• Develop relationships between PHE centres and HIV providers and commissioners of services</td>
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<td>• Secure arrangements for monitoring and accountability</td>
<td>• Ensure HIV services are fully engaged in the wider discussions and direction of travel for LTCs</td>
<td>• Take action to tackle the current variation in rates of late diagnosis</td>
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<td>• Deliver whole system stewardship with clarity about roles &amp; responsibilities across the system</td>
<td>• Support the NHS to be the best it can be in delivering HIV treatment care and provision</td>
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### The Kings Fund

Ideas that change health care