Online pilot survey of the quality of life in patients with HIV-infection in Krasnodar

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Krasnodar clinical AIDS Center (Russia)

- Overall **26 858 cases** of HIV infection.
- **2 839** registered in 2018
- Incidence of HIV - **49.2 per 100 000**
Health-related quality of life of adults living with HIV in England & Wales:

a utility analysis of EQ-5D-5L compared to the general population

Meaghan Kall
Public Health England
on behalf of the Positive Voices study group
REGIONAL PILOT ONLINE SURVEY «FEEDBACK»

MATERIALS & METHODS

- November 2018 – February 2019
- Adults randomly selected during appointed examinations
- 204 responses, item completion 88-100%
- Self-completed, web-based survey
- Descriptive and comparative statistical analysis using Statistica 10.0, Microsoft Excel 2013.

https://goo.gl/McqZv3
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MATERIALS & METHODS

Overall - 204 responses:

**Sex:**
- men – 56.9%
- women – 41.2%
- 1.9% preferred not to answer this question

**Age**  mean 36.7±8.8 / median 36

**Exposure Route**
- MSM – 19.1%
- Heterosexual – 71.4%
- Injecting drugs – 9.5%

**Other characteristics:** 35% unemployed, 86.2% on ART
PRESENTATION OBJECTIVES

1. Describe factors impacting on effectiveness of online survey
2. Evaluate data from “life satisfaction” and status disclosure
3. Present regional estimates of the met and unmet health and social needs of people accessing HIV services in Krasnodar
4. Present results on patient satisfaction from regional health care services
FACTORS IMPACTING ON ONLINE SURVEY

Technical difficulties
• Lack of Internet or Internet skills among patients
• Lack of a Google account in patients

Peculiarities of the PositiveVoices Quest.
• Duration of the survey (median 26 min)
• Section “C” is too subjective and overloaded

Unexpected
confusions when entering address

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RESULTS: LIFE SATISFACTION & DISCLOSURE

• Life satisfaction (LS) in all patients $7.0 \pm 2.3$
• “Nobody” group - LF = $6.3 \pm 1.3$
• “Friends” and “Sexual partner” LS = $7.5 \pm 1.6$ points.

![Graph showing life satisfaction levels for different groups: Friends (37.4%, LS mean 7.5), Family (65.4%), Sexual partner (59.7%, LS mean 7.5), Other people (6.6%), To nobody (8.1%, LS mean 6.3).]
RESULTS: ESTIMATION OF THE MET AND UNMET NEEDS

<table>
<thead>
<tr>
<th>What do you need?</th>
<th>HIV RELATED SERVICES</th>
<th>HEALTH SERVICES</th>
<th>SOCIAL AND WELFARE SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>E1</td>
<td>E2</td>
<td>E3</td>
</tr>
<tr>
<td></td>
<td>This section asks about your met and unmet needs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>In the last YEAR...</td>
<td>Below a list of services or help that you may have needed and/or received, in the last YEAR.</td>
<td>Below a list of services or help that you may have needed and/or received, in the last YEAR.</td>
</tr>
<tr>
<td></td>
<td>Information about living with HIV (including websites)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>HIV treatment advice</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Professional help to take your HIV tablets on time or correctly</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Peer support/social contact with other people with HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Help disclosing your HIV status</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Long term condition management support</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If you were not able to get the help</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychologist or counsellor</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Help to manage stress</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Help to manage weight</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Help or advice regarding your sex life</td>
<td></td>
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<tr>
<td></td>
<td>Help to stop smoking</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Alcohol counselling or treatment</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Drug counselling</td>
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<td></td>
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<tr>
<td></td>
<td>Chemsex support</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Drug detox or maintenance treatment</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Family planning or advice on getting pregnant</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home health services</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If you were not able to get the help</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Meaghan Kall, “Positive Voices” national survey of people living with HIV, 2017
Regional pilot online survey «Feedback»

RESULTS: MET AND UNMET NEEDS

- HIV Services:
  - Need 44%
  - Didn't need 56%
  - Unmet 24.3%

- Health Services:
  - Need 13%
  - Didn't need 87%
  - Unmet 62.5%

- Social Services:
  - Need 11%
  - Didn't need 89%
  - Unmet 87.6%

Didn't even try to get their needs:

- HIV Services: 57%
- Health Services: 79%
- Social Services: 68%
### RESULTS: HIV SERVICES VS GP RATING

<table>
<thead>
<tr>
<th>HIV services rating</th>
<th>GP rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>RU %</td>
<td>En %</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td><strong>mean</strong></td>
<td></td>
</tr>
<tr>
<td>87</td>
<td>91,4</td>
</tr>
<tr>
<td><strong>median</strong></td>
<td></td>
</tr>
<tr>
<td>90</td>
<td>96</td>
</tr>
<tr>
<td>90-100</td>
<td></td>
</tr>
<tr>
<td>65,2</td>
<td>76,4</td>
</tr>
<tr>
<td>80-89</td>
<td></td>
</tr>
<tr>
<td>14,3</td>
<td>13,3</td>
</tr>
<tr>
<td>70-79</td>
<td></td>
</tr>
<tr>
<td>8,1</td>
<td>6,2</td>
</tr>
<tr>
<td>60-69</td>
<td></td>
</tr>
<tr>
<td>2,9</td>
<td>1,8</td>
</tr>
<tr>
<td>50-59</td>
<td></td>
</tr>
<tr>
<td>4,3</td>
<td>0,7</td>
</tr>
<tr>
<td>&lt;50</td>
<td></td>
</tr>
<tr>
<td>5,2</td>
<td>1,6</td>
</tr>
</tbody>
</table>

Meaghan Kall “Patient experience with NHS HIV specialist services: results from the Positive Voices pilot survey”, 2017
CONCLUSIONS:

1) Using online-forms has its limitations

2) It’s important to inform patients how to disclose information about HIV to others

3) There are major gaps in the provision of social and welfare services

4) People living with HIV in Krasnodar region rate their HIV specialist service highly
Regional pilot online survey «Feedback»

THANK YOU!

to all survey participants
& staff at the clinical center