

'It shows we care about those issues': People living with HIVs' and care providers' qualitative needs assessment for a patient portal (Opal)

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Background

Opal is a patient portal used in oncology at the McGill University Health Centre, Montreal Canada

Opal allows patients to instantly view their lab results, diagnoses, treatment plan, appointments, and clinical notes

To optimize satisfaction and usage rates, Opal must be well-adapted to meet the specific needs of people living with HIV

Our objective is to identify the needs, recommendations, and concerns of people living with HIV and their healthcare providers to adapt Opal to HIV-specific care



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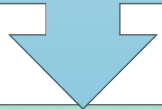
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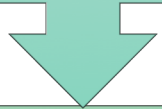
Technical / Legal

Methods


1. Our research follows a co-design methodology, recruiting individuals through purposeful sampling at: 1) the Chronic Viral Illness Service, McGill University Health Centre, 2) HIV clinics in Montreal , and 3) Infectious Disease Unit - St-Antoine Hospital, Paris, France.



2. We conducted five semi-structured focus group discussions with 24 HIV care providers (11 physicians, 7 pharmacists, 4 nurses, 1 care coordinator, and 1 social worker) and 22 HIV patients.



3. Discussions were recorded, and then transcribed by a third party. Our analysis used qualitative description and was inductively coded through NVivo 12 software.



4. Themes were generated, reviewed, and condensed. Data analysis and theme generation were performed by two researchers.

Results

- Focus group discussions displayed four major recurring themes. Patients had needed, recommended, or were concerned about:

1. Simple patient-oriented information

- Includes diagnoses, interpretation of lab results, and treatment plans. Also includes education material informing patients of criminality in HIV, immigration, socioeconomic relief, and patient rights.

2. Adaptable and user-friendly settings for key functions

- Appointment management, prescription-renewal reminders, medication adherence support, and intra-hospital navigation.

3. Access to communication tools

- Provision of patient reported outcome measures, patient-provider texting, and contact information.

4. A secure and private patient portal

- A password to enter the portal, strong data security, and no obvious text or images that suggest the portal is specifically for HIV patients.

Conclusions

Portal Development

- Stakeholders express a need for a diverse range of patient portal functions and recommendations
- Concerns focus around privacy, maintaining confidentiality, and data security

Stakeholder Expectations

- Stakeholders expect promotion of psychosocial support
- Participants' expectations are that Opal will improve healthcare for HIV patients
- Participants emphasize the importance of promoting multi-disciplinary involvement and patient engagement

Future Considerations

- Our results highlight the importance of involving stakeholders in the development of a specific patient portal
- The patient portal could ideally provide a framework for future patient portal development in other specific fields

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