INTRODUCTION

- easyPod™ is an electromechanical actuator used for the administration of recombinant human growth hormone (r-hGH; Sanofi® Merck KGaA, Darmstadt, Germany).
- Healthcare professionals (HCPs) receive adherence information on Sanofi® treatment via data wirelessly transferred from the easyPod® device to the web-based eHealth platform easyPod® Connect.
- The growlink™ mobile app is being developed in order to empower parents and caregivers with adherence information and provide education tools.
- A comprehensive approach was followed during the design phase, incorporating the views of patients and caregivers and aligning with their expectations.
- Initial assumptions for app design were that:
  - patients and caregivers would like two independent apps to satisfy the needs of each group;
  - patients would appreciate the use of serious video game elements to improve their experience and engagement (known as gamification);
  - ‘Younger’ and ‘older’ patient user groups were chosen because teenagers and children see at different stages of treatment and there is a concept that teenagers get less compliant as they get older.

METHODS

- This was a two phase user research group study.
- Patients receiving r-hGH and caregivers were recruited from three UK societies: The Pituitary Foundation, Turner Syndrome Support Society and the Child Growth Foundation.
  - Round One took place in Birmingham and London (younger patients and caregivers);
  - Round Two took place in London (older patients and caregivers).
- Four concepts for the growlink™ app (Figure 1) were developed using an agile design process. The design process included:
  - a literature review of growth apps;
  - a literature review of growth apps;
  - previous feedback received from patients and their caregivers;
  - traditional resources (e.g. children’s red book in the UK, held by caregivers).
- Proposed app features included:
  - adherence information;
  - height and weight growth graphs with reference curves;
  - an ability to customise;
  - separate versions for patients and caregivers.

RESULTS

Patient characteristics

- All patients and caregivers were from the UK.
- The Round One user group comprised younger patients and caregivers of younger patients (mostly < 10 years of age);
- One female patient, 19 years of age, receiving r-hGH treatment was interviewed separately.
- The Round Two user group comprised older patients and caregivers of the older patients.

Table 1. Patient and caregiver characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Round One - younger</th>
<th>Round One - older</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient (n=5)</td>
<td>Patient (n=5)</td>
<td></td>
</tr>
<tr>
<td>Age, years</td>
<td>10.25 (1.88)</td>
<td>14.6 (1.14)</td>
</tr>
<tr>
<td>(Min. Max.)</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td>Male 4, Female 1</td>
<td>Male 5</td>
</tr>
<tr>
<td>T. Syndrome</td>
<td>Yes 4, No 1</td>
<td>Yes 5</td>
</tr>
</tbody>
</table>

Table 1. Patient and caregiver characteristics

- Some caregivers were concerned that tracking adherence could lead to being judged by HCPs.
- Some caregivers expressed an interest in tracking adherence information once the patient started administering doses.

Round One user group opinion

- Patients and caregivers were shown app design concepts 1–4 (Figure 5).
- Adherence
  - Younger patients and caregivers did not find adherence data as alerts relevant as an r-hGH medication was taken as part of a routine (e.g. bedtime).
- Some caregivers were concerned that tracking adherence could lead to being judged by HCPs.
- Some caregivers expressed an interest in tracking adherence information once the patient started administering doses.
- Weight and height measurements
  - Younger patients and caregivers felt height and weight measures were strongly motivating.
- Some caregivers voiced concerns that goals needed to be achievable and that poor growth could be demotivating.

Round Two user group opinion

- Older patients and caregivers did not want separate versions of the app.
- Customisable
  - Younger patients and caregivers wanted the app to be customizable.

Emotive elements

- Caregivers of younger patients liked the use of images and measurements to show the patient journey over time.
- Improvements
  - Concept 1 (Figure 1. 3) was the favourite of both patients and caregivers.
  - The strong and vibrant look and feel and card-based layout was improved and carried forward to Round Two (Figures 2–6).
- Adherence
  - Less emphasis was placed on missed injections on the dashboard while maintaining adherence information;
  - The growth add-on from concept 1 was featured in this new design along with the ability for caregivers to document their child’s ‘journey’.
- Weight and height measurements
  - Customisable
  - Older patients and caregivers wanted the app to be customisable.
- Gamification
  - Overt gamification was not liked by patients or caregivers.

Future directions

- The growlink™ app (Figure 6) has been developed based on the Concept 3 design (Figures 2–4) and patient/caregiver feedback:
  - No gamification or serious games.
  - Both groups wanted the same app and features.
  - Clear adherence information featuring monthly and yearly outputs;
  - Helpful tips linking to education;
  - Clear growth graphs with reference curves selected by the HCP;
  - Patients and caregivers can wirelessly receive adherence information from easyPod® Connect via the growlink™ app and it:
    - Has been awarded a CE mark, medical class I;
    - is undergoing a pilot in Sweden and has been approved for a pilot in the UK.

CONCLUSIONS

- A prior assumption on certain app design features were challenged:
  - Gamification;
  - Two independent apps to satisfy the needs of each group.
- At odds with assumptions, a similar sharing of values between caregivers and patients was revealed.
- Whilst HCPs stress for monitoring, patients and caregivers would prefer clear reference based motivating and non-judgemental messages over time.
- The user research gave valuable insights that were fed back into the ongoing pilot.

REFERENCES

- Thomsen, S. et al. CHI’11 extended abstracts on human factors in computing systems (pp. 2425-2428). ACM.

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DISCLOSURES

- The authors declare no conflict of interest.

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1. The calendar gives a monthly and yearly view of adherence; 2. Schedule and adherence outcomes are displayed on a dial; 3. The user can add a add photo at the end of the process before returning to the Wall; 4. The caregiver can enter an anecdote at the end of the process before returning to the Wall.

Figure 1. Four app design concepts

Figure 2. Improved app concept 3. My Wall

Figure 3. Improved app concept 3. Injections

Figure 4. Improved app concept 3. Graphs

Figure 5. Study flow

Figure 6. Pilot growlink™ app