

Patients and caregivers perspectives on a mobile app that tracks adherence and outcomes in children with growth disorders treated with recombinant human growth hormone (r-hGH)

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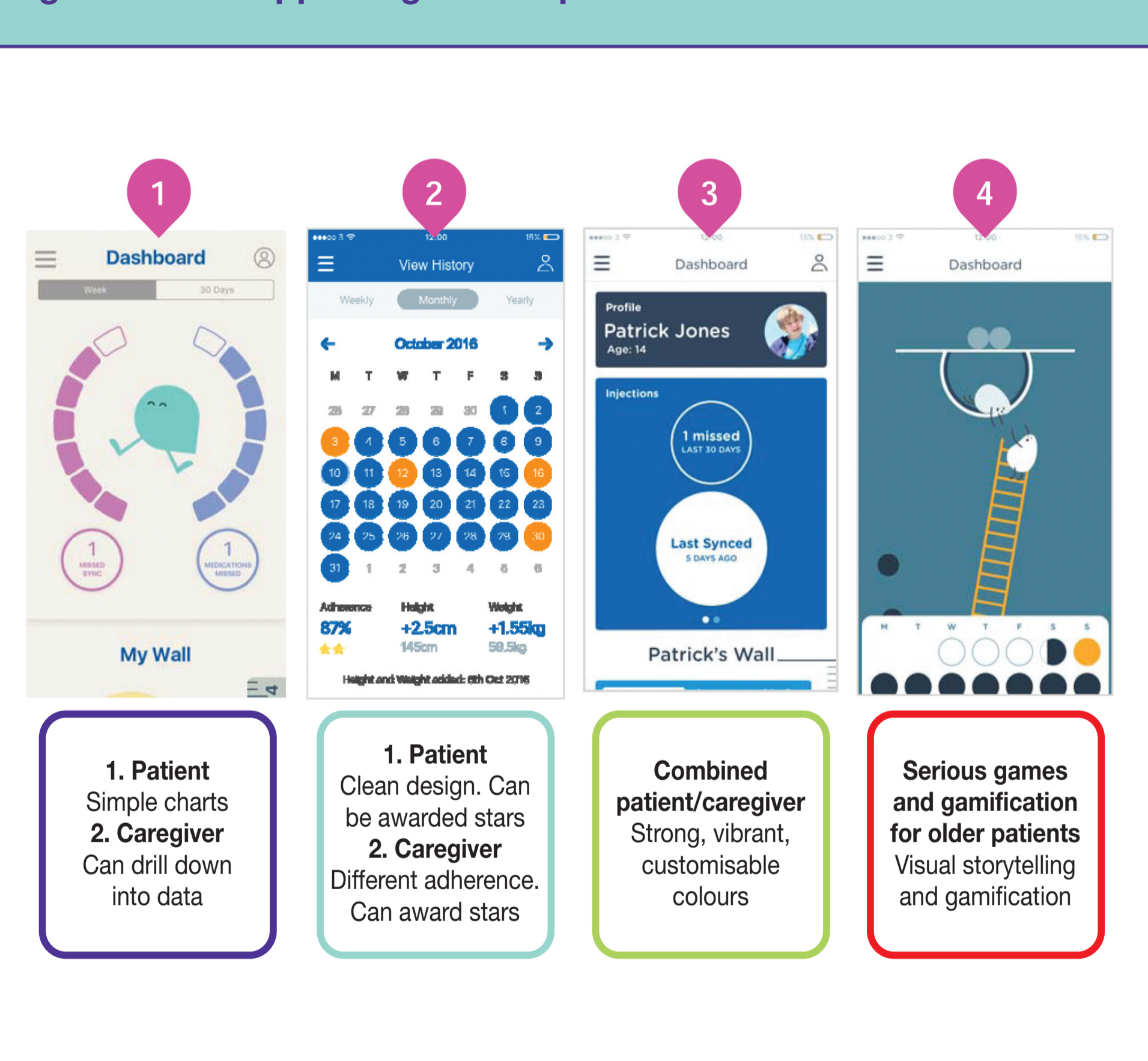
INTRODUCTION

- easypod™ is an electromechanical autoinjector used for the administration of recombinant human growth hormone (r-hGH; Saizen®, Merck KGaA, Darmstadt, Germany).
- Healthcare professionals (HCPs) receive adherence information on Saizen® 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 patients and caregivers with adherence information and provide education tools.
- A user-centric 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 gamification¹).
- 'Younger' and 'older' patient user groups were chosen because teenagers and children are 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 rGH and caregivers were recruited by 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.² The design process included:
 - a benchmarking review of growth apps;
 - a literature assessment of clinical practice;
 - 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.

Figure 1. Four app design concepts



RESULTS

Patient characteristics

- All patients 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 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

Variable	Round One - younger		Round Two - older	
	Patient (n=5*)	Caregiver† (n=9)	Patient (n=5)	Caregiver† (n=5)
Age, years Mean (SD) Min; Max	10.25 (1.89) 9; 13*	-	14.6 (1.14) 13; 16	-
Gender, n (%)				
Male	4	1	2	1
Female	1*	8	3	4
Turner syndrome‡, n	-	-	3†	-
hGH treatment Naïve Y/N	N	N	N	N

*One female patient, 19 years of age, receiving hGH treatment, without Turner syndrome was interviewed separately and not included in the Round One average age; †females; ‡caregivers were all parents of children receiving hGH treatment; §Short stature was not specified for all other patients.

Round One user group opinion (Younger patients and caregivers)

- Patients and caregivers were shown app design concepts 1-3 (Figure 5).
- Adherence**
 - Younger patients and caregivers did not find adherence data or alerts relevant as 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 wanted to see clear growth graphs with reference curves.
- 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 demoralising.

Two independent apps to satisfy the needs of each group

- Younger patients and caregivers did not want separate versions of the app.

Customisable

- Younger patients and caregivers wanted the app to be customisable.

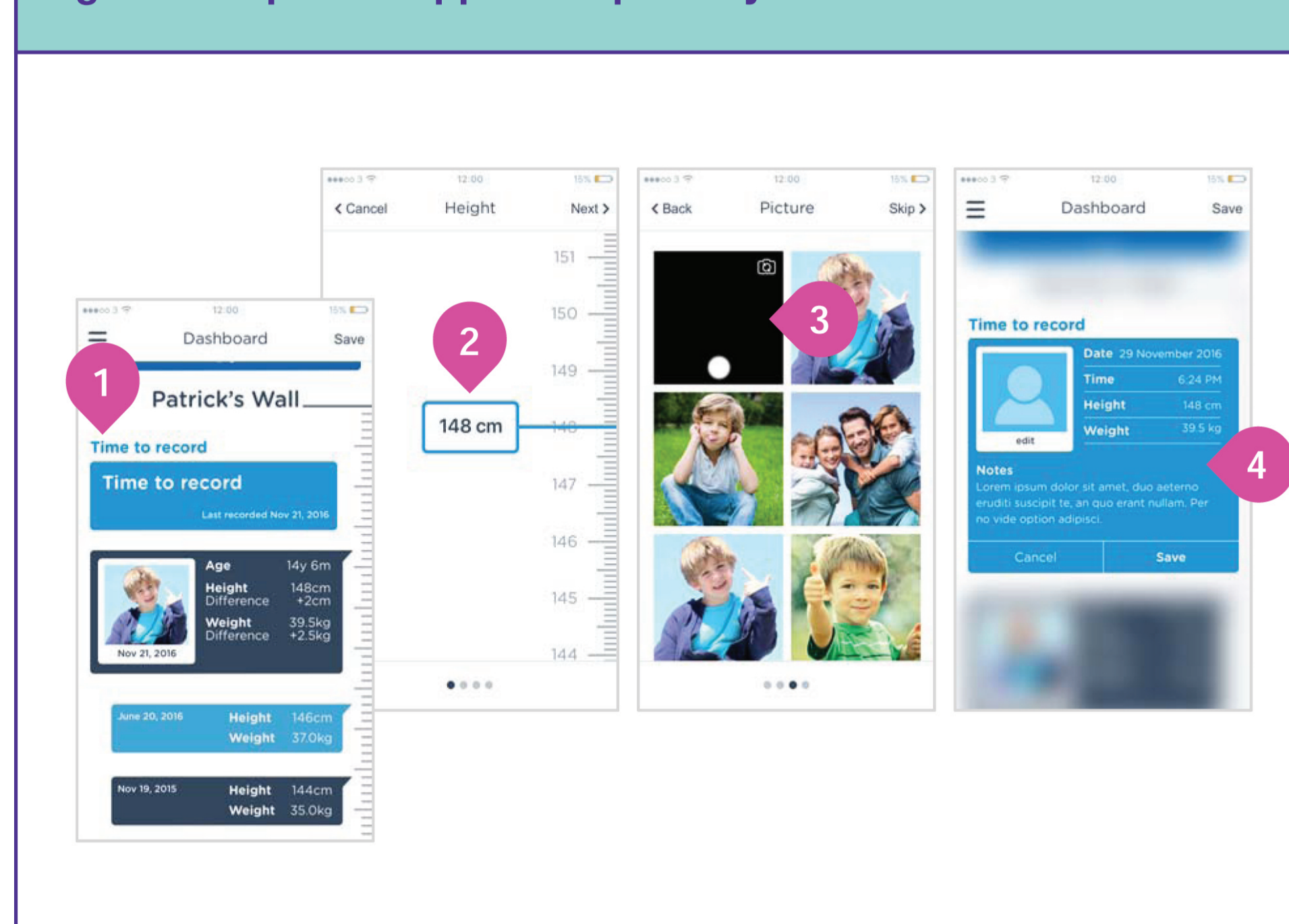
Emotive elements

- Caregivers of younger patients liked the use of images and measurements to show the patient journey over time.

Improvements

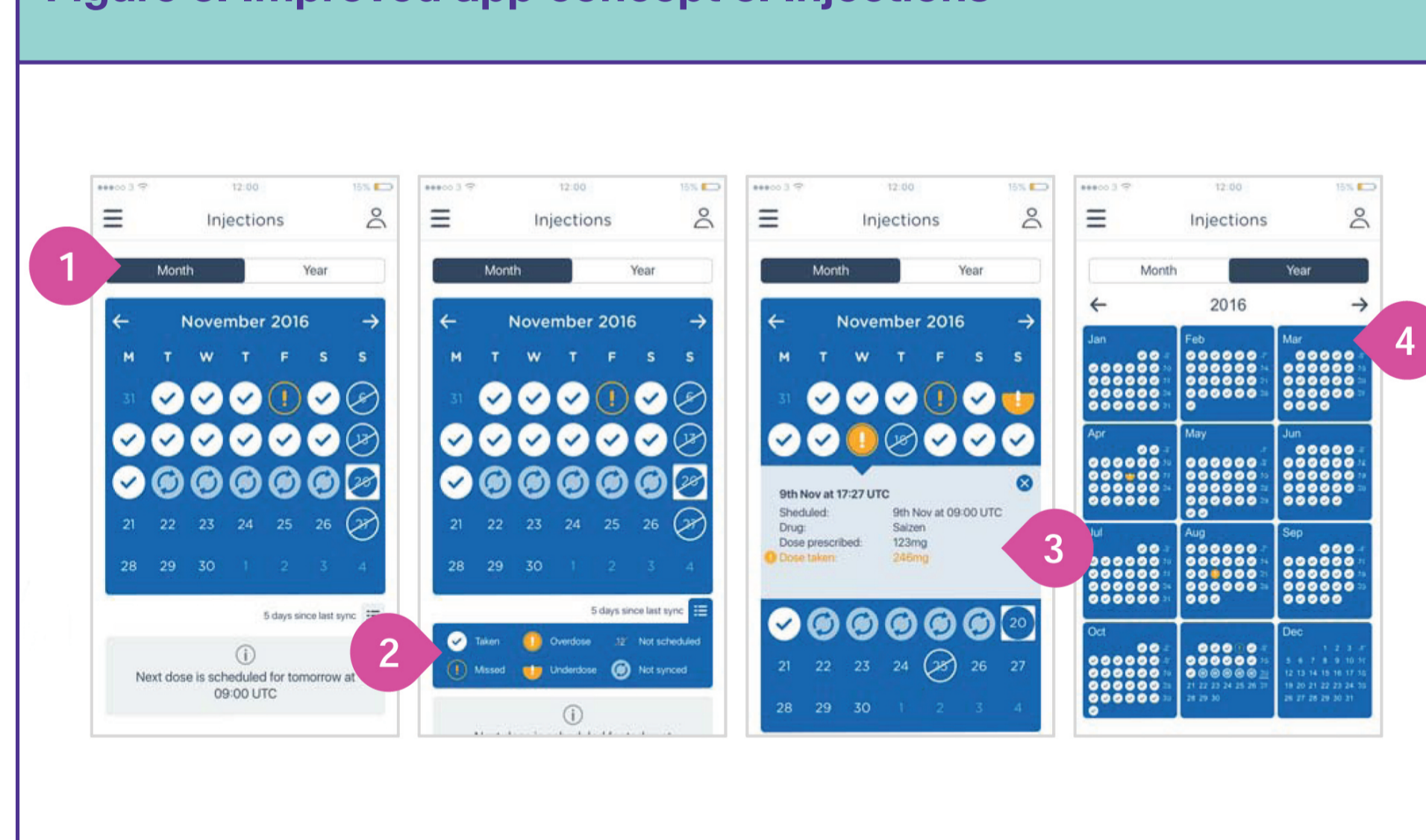
- Concept 3 (Figure 1, 3) was the favourite of both patients and caregivers.
- The strong and vibrant look and feel and card-based layout was improved and carried forward to Round Two (Figures 2-4):
 - Less emphasis was placed on missed injections on the dashboard while maintaining adherence information;
 - The growth wall from concept 1 was featured in this new design along with the ability for caregivers to document their child's 'journey';
 - Particular focus was given to details in the graphs.

Figure 2. Improved app concept 3. My Wall



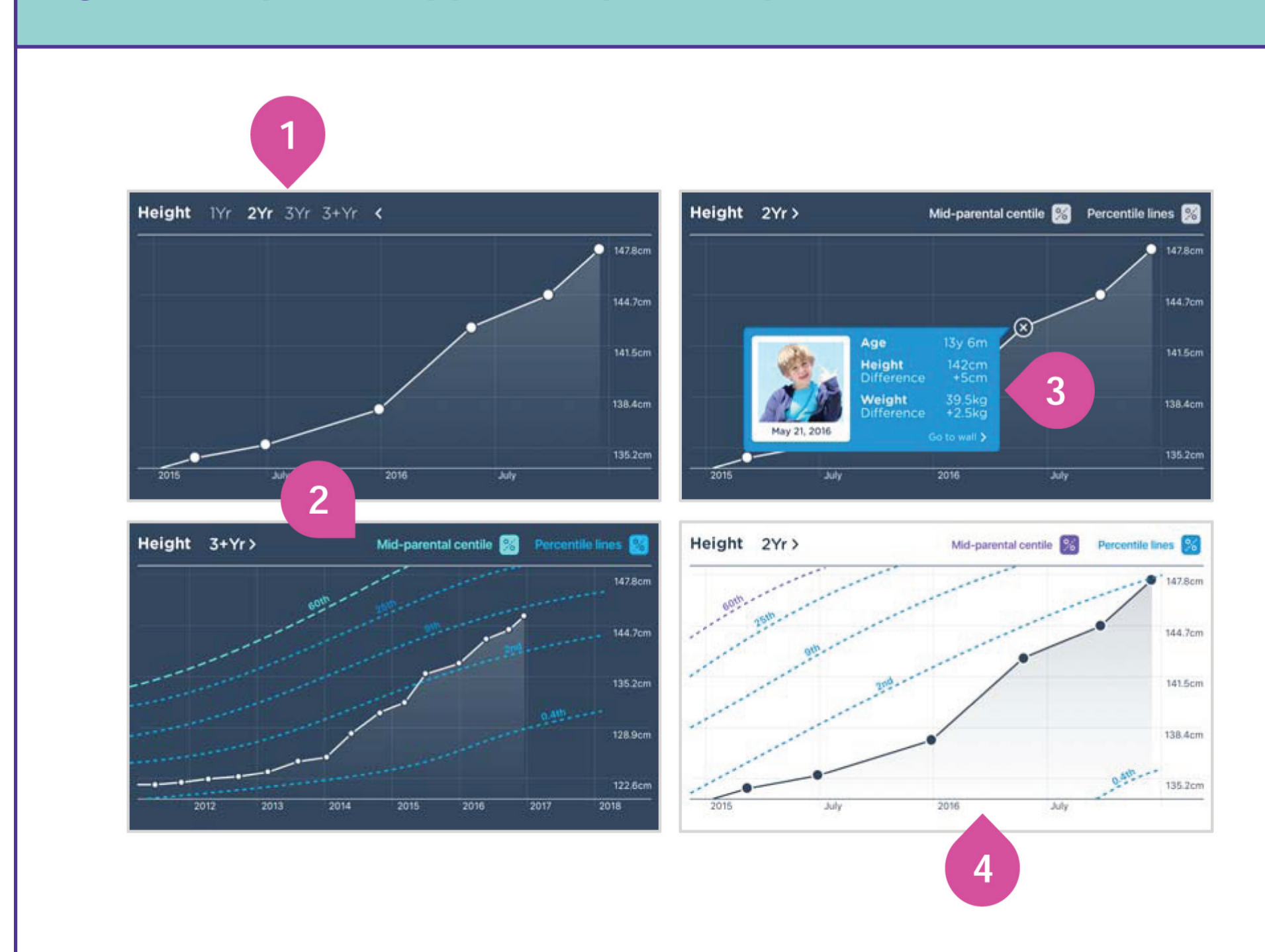
1. Nudges will alert users if they have not recorded height for some time; 2. A vertical ruler is used for recording - which streamlines the transition between the Wall; 3. The caregiver is prompted to add a photo and can enter anecdotes; 4. The caregiver can also enter anecdotes at the end of the process before they return to the Wall.

Figure 3. Improved app concept 3. Injections



1. The calendar gives a monthly and yearly view of adherence; 2. Schedule and adherence outcomes are represented by an icon; 3. Daily information can be retrieved by tapping on a date; 4. The year view reveals a complete picture of adherence.

Figure 4. Improved app concept 3. Graphs

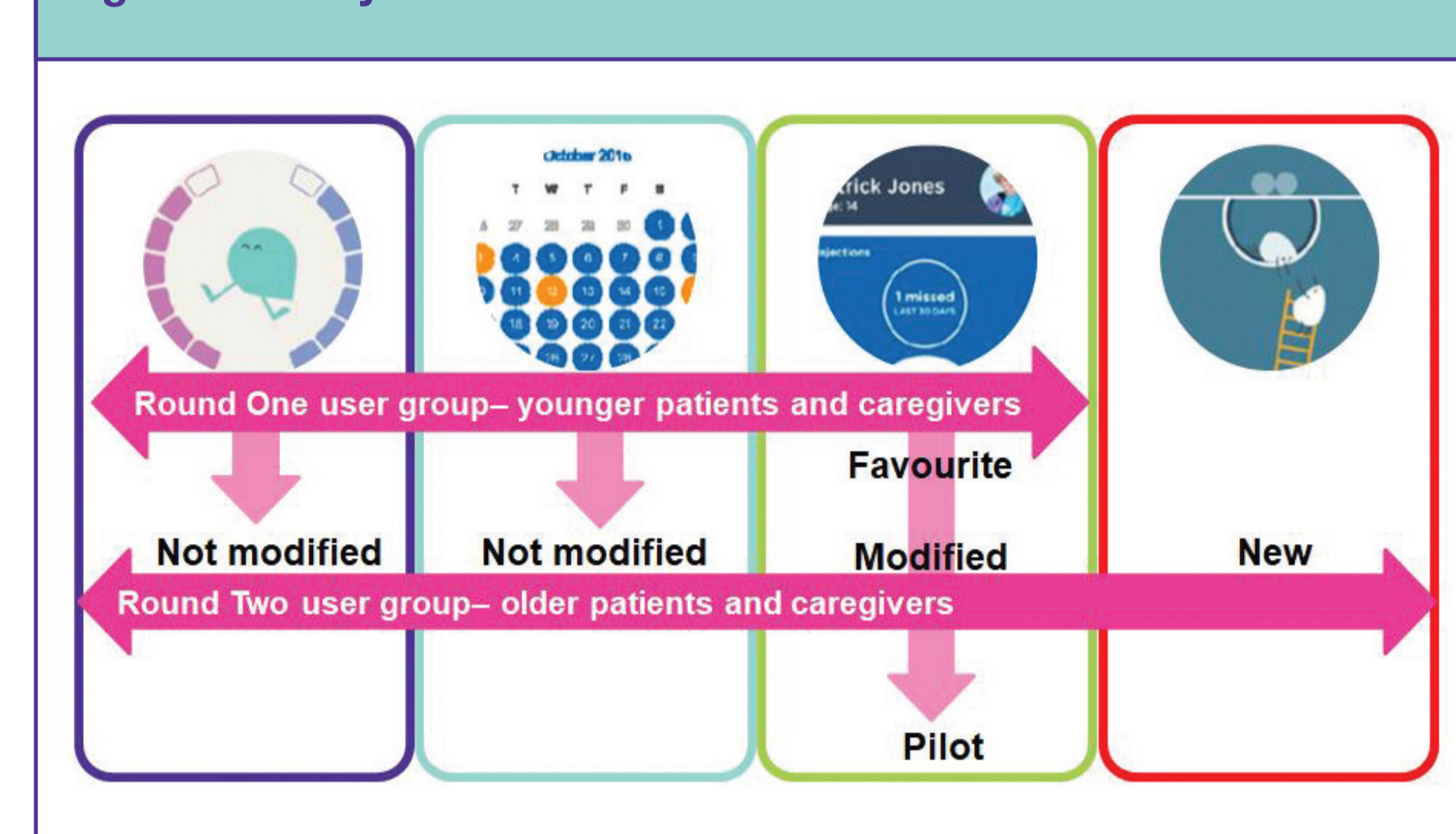


1. A full screen version of the graph is presented when the phone is sideways; 2. Percentile lines can be turned on and off; 3. Tapping on a data point reveals precise metrics for that date; 4. An alternative graph style.

Round Two user group opinion (Older patients and caregivers)

- Patients and caregivers were shown the original and revised apps as well as an app incorporating games and gamification 1-4 (See Figure 5 for Study flow).

Figure 5. Study flow



Adherence

- Older patients and their caregivers liked seeing adherence as they found it useful for reviewing before meeting their HCPs:
 - They considered adding a note to missed doses could be useful.

Weight and height

- Older patients and their caregivers wanted to see clear height growth graphs with reference curves.
- Caregivers reported patient sensitivities around weight data.

Two independent apps to satisfy the needs of each group

- Older patients and caregivers did not want separate versions of the app.

Customisable

- Older patients and caregivers wanted the app to be customisable.

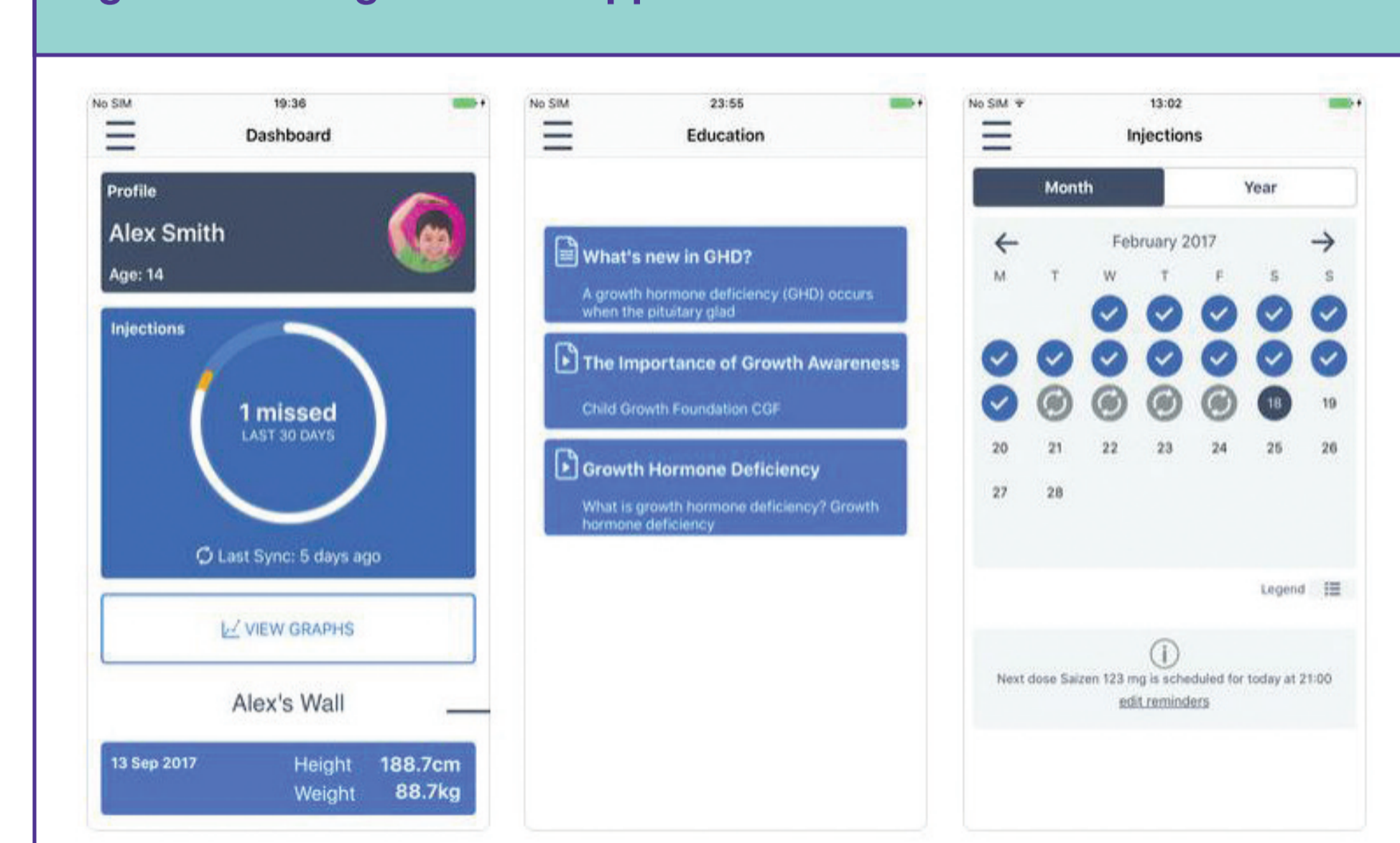
Gamification

- 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 out 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.

Figure 6. Pilot growlink™ app



CONCLUSIONS

- A priori assumptions 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 strive 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

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DISCLOSURES

Jorge Cancela, Ekaterina Koledova and Javier Sanchez Castro are employees of Merck KGaA, Darmstadt, Germany. Ekaterina Koledova has received honoraria and research grants from Merck KGaA, Darmstadt, Germany.



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