PKU Toolkit for Return to diet
Virtual group programme

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Aims:
Register a minimum of 10 off-diet/non-compliant adult PKU patients to attend 5 educational sessions; to include patients seeking further support and information.

Concept:
5 virtual sessions, covering 5 distinct topics. Hosted fortnightly on Saturday mornings from January - March 2021. Each included key speakers, lasting 90-120mins.

Patient adherence prior to attending the PKU Toolkit

Patient adherence with diet and protein substitutes immediately after attending the course

<table>
<thead>
<tr>
<th>Off diet - Did not follow the low protein diet and rarely/never took protein substitute</th>
<th>Sometimes followed my low protein diet and sometimes took protein substitute</th>
<th>Sometimes followed my low protein diet and took all protein substitute</th>
<th>Always followed my low protein diet and took some protein substitute</th>
<th>Always followed my low protein diet and took all protein substitutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

No patients had previously attended a similar course

17 patients registered their interest

13 final feedback forms were completed

2 attended only 1/5 sessions

2 did not attend due to other commitments

14 patients registered their interest

13 final feedback forms were completed

2 attended only 1/5 sessions

2 did not attend due to other commitments

17 patients registered their interest

13 final feedback forms were completed

2 attended only 1/5 sessions

2 did not attend due to other commitments
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Virtual group programme

Virtual Group Topics and Engagement during each session

<table>
<thead>
<tr>
<th>Session topic</th>
<th>Duration</th>
<th>Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intro &amp; Dietary Information</td>
<td>114 min</td>
<td>363</td>
</tr>
<tr>
<td>Physical Activity &amp; wellbeing</td>
<td>93 min</td>
<td>97</td>
</tr>
<tr>
<td>Mental Health &amp; Wellbeing</td>
<td>94 min</td>
<td>177</td>
</tr>
<tr>
<td>Cooking Demo (Jackfruit carbonara, pie with ratatouille, banana muffins)</td>
<td>90 min</td>
<td>133</td>
</tr>
<tr>
<td>Getting Benefits (PIP); Summary; Goal setting &amp; feedback</td>
<td>100min</td>
<td>71</td>
</tr>
<tr>
<td>Total</td>
<td>8hr 11m</td>
<td>838</td>
</tr>
<tr>
<td>Average</td>
<td>98 min</td>
<td>168</td>
</tr>
</tbody>
</table>

Patient feedback at the end of the course

- It was amazing really helped me and encouraged me to talk more about it with my partner and helped him gain knowledge in an informal way.
- I really enjoyed this course, and I think it would be great to have more in the future. Found out a lot of new things, and got a lot of resources and information I will use in the future.
- I found this course helped my mindset and motivation to keep to my diet.
- Really informative and a great way to motivate yourself and others to learn new things and help, support and encourage.
- Thank you so much for hosting this it has been amazing and for all the material support that you have sent. It has been greatly appreciated and so helpful.
- Thank you so much I have learned a lot and give me the confidence to stay on diet, the support means a lot.

Virtual Group - added benefits

- A means of reaching a wider PKU audience, possibility to engage patients who don’t always attend clinics.
- Innovative, yet accessible way of engaging with patients.
- Increase peer support in long term condition and self-management.
- Promoting a PKU lifestyle concept to create an online “wellness” community long term.
- Enhanced patient learning as the patients are within their own environment, reduced anxiety and stress.
- Supporting services to meet gaps in patient support and education e.g. psychology or mental health help.
- Low environmental impact and lower cost.
- Potential to run as ongoing patient education programme regionally or nationally.