

| Group rank from 2 <sup>nd</sup> survey | People with CF  | Family & Friends  | Health care professionals & researchers  | People with CF not on modulator therapy  |
|--|---|---|--|--|
| 1                                      | What are the long-term effects of CFTR modulators?*   | Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?                                      | What are the long-term effects of CFTR modulators?*  | Are options available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)? |
| 2                                      | Are people with CF at higher risk of certain cancers and what is the best way to detect and manage cancers in people with CF?                   | What are the long-term effects of CFTR modulators?*   | Are options available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)?       | Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?                                 |
| 3                                      | Are options available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)?      | Are options available for those not able to take current CFTR modulators (including rarer mutations, not eligible and unable to tolerate)?      | What are the effective ways of simplifying the treatment burden of people with CF?   | How best to manage and support people with CF post-transplantation (e.g. mental health, rejection, modulator use)?                         |
| 4                                      | Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?                                      | What are the effects of modulators on systems outside the lungs such as pancreatic function, liver disease, gastrointestinal, bone density etc? | Can genetic therapies (such as gene editing, stem cell and mRNA technology) be used as a treatment for CF?                                       | How to improve breathing capacity/lung volume?   |
| 5                                      | What are the effects of modulators on systems outside the lungs such as pancreatic function, liver disease, gastrointestinal, bone density etc? | What is the optimum treatment regimen for eradication of Pseudomonas in people with CF?   | What is the best way to diagnose lung infection when there is no sputum e.g. children and those on modulators?                                   | Is there a way of reducing the negative effects of antibiotics e.g. resistance risk and adverse symptoms in people with CF?                |
| 6                                      | How do we manage an ageing population with CF?  | What are the effective ways of simplifying the treatment burden of people with CF?  | What are the effects of modulators on systems outside the lungs such as pancreatic function, liver disease, gastrointestinal, bone density etc.? |  |
| 7                                      | How can we recognise and manage the side-effects of CFTR modulators (including those at greater risk e.g. liver disease)?                       | Is there a way of preventing CF related diabetes (CFRD) in people with CF?  | How do we manage an ageing population with CF?   |  |
| 8                                      | How can we relieve gastro-intestinal symptoms, such as stomach pain, bloating and nausea?   | How can we recognise and manage the side-effects of CFTR modulators (including those at greater risk e.g. liver disease)?                       | What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?                      |  |
| 9                                      | Is there a way of preventing CF related diabetes (CFRD) in people with CF?  | How can we relieve gastro-intestinal symptoms, such as stomach pain, bloating and nausea?   | Is there a way of preventing CF related diabetes (CFRD) in people with CF?   |  |
| 10                                     | How to improve breathing capacity/lung volume?  | What are the long-term effects of medications for CF?*  | Can exercise replace chest physiotherapy in people with CF?  |  |

Supplement 1: Table showing the questions taken forward from the ranking survey to the final workshop for each group. \* marks questions that were merged into a new question “What are the long-term effects of medications (including CFTR modulators) in CF?” on management group consensus as felt to be too similar.