

Specialist Topic guide

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Typical care methods:

How is your ACHD outpatient service organised?

For example, how often are clinics, how many patients come, what staff are involved.

How are patients advised to manage their condition outside of healthcare?

Describe a (general outpatient) clinic appointment with an adult congenital patient?

What do the different types of interaction with your patients look like?

How well do you think your ACHD outpatient system works?

Do you feel like this care works well for the patient?

How satisfied do patients seem with this level of care.

Do you feel like the resources are used appropriately? Are they wasted? Are they insufficient?

Would you change this interaction? How?

Can you summarise in a few sentences what you think are the key goals of outpatient care for adults with congenital heart disease?

Do you feel like you manage to achieve these with the current availability of resources?

If no, what is the limitation on resources? Who do you think is responsible?

A recent study (Coats & Chaudhry, 2021) found 80% of ACHD clinic appointments result in no decision other than continued surveillance. How does this compare to your personal experiences?

How do you feel about recurring clinic appointments without changing treatments?

What does a sufficiently cared for patient look like?

What would you need to do to achieve this level of care for your current patients?

33 **Describe the transition of patients from paediatric care to adult care at your centre.**

34 **How does it compare with other centres that you know about.**

35 How effective do you feel your transition process is?

36 What changes would you make if there were no financial limitations.

37 Are there any changes you would make that could save money or deliver better transition
38 with the same cost?

39

40 **Is nonattendance an issue for your clinic?**

41 What percentage of appointments are missed?

42 What are the reasons that lead to nonattendance for your patients?

43 How do you manage non-attendance in your clinic?

44

45 **Describe any changes that were made to care provision during Covid?**

46 Do you plan to continue some or all, or will you return to previous systems?

47 Explain why.

48

49 **Individuality of patient care:**

50

51 **What challenges do you face when caring for different adults with CHD?**

52 Do you have to cater to different requirements based on culture?

53 How well do you manage these challenges?

54 Do you feel there would be a good way to plan for this?

55

56 **Can you describe any differences in care provision for patients with differing
57 complexity of congenital heart disease?**

58 How well is care presently co-ordinated?

59 What aspects could be improved to meet individual needs?

60 How do you co-ordinate with cardiologist in other centres? Does this relationship work well?

61 Are there any difficulties you experience? What could improve things?

62

63 **Is there anything special about the doctor-patient relationship for adults with CHD?**

64 How do you manage patients who are not trusting of healthcare?

65 How do you manage patients who feel neglected by healthcare system?

66 What happens if a patient stops attending clinics?

67

68 **Accessibility of services:**

69

70 **What do adults with congenital heart disease need to know about their condition?**

71 Do you find any difficulty communicating particular aspects?

72 What are these, what could help you?

73 How is information made available to patients about their condition?

74 Is it provided to patients, or must they look for it?

75 How helpful do you think available resources are?

76 Do you feel like patients are educated sufficiently on how to care for themselves?

77

78 **How frequently are patients encouraged to attend clinics?**

79 What other types of care and services are available to your patients?

80 Do you feel like the current provision of outpatient care works?

81 Do patients need to travel for this - how far is a typical distance to travel?

82 Could care be provided in a different way?

83

84 **Psychological Support:**

85

86 **Which aspects of a patient's condition/care do you believe cause them anxiety?**

87 What causes anxiety and worry for you?

88

89 **To what extent do you believe psychological support should be available to outpatients?**

90 How are patients advised to support themselves in their condition?

91 How do you ensure patients are supporting themselves?

92 Do you provide psychological resources?

93 Is psychology support better provided in the specialist centre or primary care?

94

95 **Describe how you would improve psychological care for patients?**

96

97

98

- 99 **Other Chronic Disease Models:**
- 100
- 101 **What awareness do you have of how other adults with chronic disease manage their**
- 102 **conditions, for example diabetes or cystic fibrosis?**
- 103 Is this something that could work for adults with CHD?
- 104 What problems do you foresee for adults with CHD?
- 105
- 106 **What aspects of healthcare could ACHD patients self-manage?**
- 107 Which areas should stay under clinician control?
- 108 Could anyone else help support adults with CHD in managing their health?
- 109
- 110 **Which mobile health technologies might be suitable for use in adults with CHD?**
- 111
- 112 **How does primary care presently support adults with CHD?**
- 113 What are the problems with how this system works at present?
- 114 What could work better?
- 115 Could a more proactive role be developed?
- 116
- 117 **Is there anything we haven't covered which might be important to think about in**
- 118 **providing ambulatory care for adults with CHD?**
- 119
- 120
- 121
- 122 **Non-specialist Cardiologist topic guide:**
- 123
- 124 **Typical care methods:**
- 125
- 126 **Can you describe your experience of interacting with adult congenital heart disease**
- 127 **patients?**
- 128 How frequently do you care for ACHD patients, what does this look like?
- 129 How is care for these patients organised in your hospital?
- 130 How does your interaction with the specialist centre work?
- 131 What conditions do you feel happy managing in your centre? What do you need help with?

132 What are you uncomfortable managing?

133 How common do you believe ACHD to be? – Incidence of 3-4/1000.

134

135 **What are your goals when interacting with ACHD patients?**

136 Are resources easily accessible to support you in your care for them?

137 Can you get the advice you need? Have you ever experienced problems knowing how to get
138 the right advice?

139

140 **How do you feel about patient care in hospital outpatient clinics?**

141 How does the current outpatient clinic care provision affect the care you provide?

142 Do you feel like patient experience could be improved through a change in your role? How?

143

144 **A recent study (Coats & Chaudhry) suggested 80% of hospital appointments for ACHD
145 patients result in no decision other than continued surveillance.**

146 What are your thoughts about this? How do hospital clinics affect your workload?

147 Other than outpatients, in what other ways might surveillance work well?

148

149 **What do you feel are the costs to patients with the current way specialist and general
150 cardiology outpatients and primary care function? What are the costs for healthcare**

151 **providers? Is there a different way to do things that might work better?**

152

153 **What does a sufficiently cared for patient look like?**

154 How do you achieve this level of care for a patient?

155 How do you feel about the current number of patients receiving insufficient care?

156

157 **Do you feel like patients are satisfied with their level of care?**

158 Do you feel like the current care system is sufficient for patients?

159 What resources are provided to patients? Are they used sufficiently?

160

161 **Are there changes during COVID that could be continued that you have seen resulting
162 in improved satisfaction and reduced burden for patients or healthcare providers?**

163

164

165 **Individuality of patient care:**

166

167 **What challenges do you face when caring for different adults (with or without CHD)?**

168 **May need to provide examples (ethnicity, learning difficulties, mental health,**
169 **socioeconomic status)**

170 Do you have to cater to different requirements based on culture etc.?

171 Do you have support systems in place that help with this?

172 How do you manage these challenges?

173

174 **How well is care presently co-ordinated between centres and what aspects could be**
175 **improved to meet individual patient needs?**

176

177

178 **Accessibility of services:**

179

180 **What challenges do you face when caring for different adults in your clinic?**

181 Do you have to cater to different requirements based on culture?

182 How well do you manage these challenges?

183 Do you feel there would be a good way to plan for this?

184

185 **How well informed about their condition are adults with congenital heart disease in**
186 **your experience?**

187 Do you notice that some people with certain conditions are better informed than others? Can
188 you describe some of these differences?

189 Do you ever have difficulty communicating particular aspects of congenital heart disease?

190 Can you give an example? What type of information do you find works well for informing
191 patients?

192 Do you feel like patients are educated sufficiently on how to care for themselves?

193

194 **Psychological Support:**

195

196 **What aspects of a patient's condition/care do you believe cause them anxiety?**

197 What causes anxiety and worry for you?

198

199 **To what extent do you believe psychological support should be provided to those**
200 **with chronic disease? What is your experience of anxiety and depression in those**
201 **with chronic conditions?**

202 How are patients advised to support themselves in their condition? How do you ensure
203 patients are supporting themselves?

204 Do you provide psychological resources? Where should they best be provided?

205 Describe how you would improve psychological care for patients?

206

207 **Other Chronic Disease Models:**

208

209 **What is your awareness of how other adults with chronic disease manage their**
210 **conditions, for example diabetes or cystic fibrosis?**

211 Is this something that could work for adults with CHD? What problems do you foresee for
212 adults with CHD?

213

214 **What do you think is the present role for primary care in supporting adults with CHD?**

215 What are the problems with how this system works at present?

216 What could work better? Could a more proactive role be developed?

217

218 **What aspects of healthcare could ACHD patients self-manage?**

219 Do you have experience of other cardiac patients who self-manage aspects of their
220 condition? What things work well? Which areas should stay under clinician control?

221 Could anyone else help support adults with CHD in managing their health?

222

223 **Do you have experience of using any mobile health technologies in adults with**
224 **cardiac disease?**

225 What has worked well? What has caused problems? Do patients like mobile technology?

226

227 **Is there anything we haven't covered which might be important to think about in**
228 **providing ambulatory care for adults with CHD?**

229

230

231 **GP prompt guide**

232

233 **Typical care methods:**

234

235 **Could you describe any experience you have of patients with adult congenital heart**
236 **disease? (Or chronic illnesses/heart conditions if not)**

237 - What does your interaction with patients look like?

238 - How much responsibility do you FEEL you have for patients with a heart condition/chronic
239 condition, as a primary care provider?

240 - Could you describe any changes you would make to the current level of interaction you have
241 with patients with heart conditions/chronic conditions? How?

242

243 **How common do you think ACHD is? - Incidence of 8/1000 people in developed**
244 **countries.**

245 - Do you feel like you are aware of all the patients who are registered with your practice who
246 have ACHD?

247 - Is there a plan for managing common issues in ACHD ie pregnancy, birth control, exercise?
248 Do you feel like a plan would improve care?

249

250 **Could you describe how you presently support adults with CHD in the primary care**
251 **service?**

252 - What are the problems with how this system works at present?

253 - What could work better?

254 - Could a more proactive role be developed?

255

256 **What are your key goals when interacting with patients in general?**

257 **Does this change at all when interacting with patients with heart conditions?**

258 - Do you feel like you manage to achieve these goals with the current availability of
259 resources?

260

261 **What does a sufficiently cared for patient look like? Is this different for a patient with**
262 **a known heart condition/chronic condition?**

263 - How do you achieve this level of care for a patient?

264

265 **Could you describe the changes that were made to maintain patient care during**
266 **COVID?**

267 - Could any of these changes be continued post-pandemic?

268

269 **Individuality of patient care:**

270

271 **What challenges do you face when caring for different patients?**

272 - Do you have to cater to different requirements based on culture, age etc? do you feel there
273 would be a good way to plan for this?

274 - Are there challenges due to these different requirements?

275 - How do you manage these challenges?

276 - How relevant is a patients chronic/heart condition when they approach you for general
277 queries/health advice?

278 - Do you approach patients with chronic conditions (heart conditions) differently?

279 - Is the level of a patient's education on their condition a factor in this?

280

281 **To what extent do you incorporate patient's own knowledge of their condition into**
282 **care?**

283 Would you change this?

284

285 **How well is care presently co-ordinated and what aspects could be improved to meet**
286 **individual needs?**

287 Do you feel you are provided with sufficient information regarding ACHD/heart condition
288 patient's condition, in order to properly care for them?

289 Do you feel you have sufficient contact/communication with other areas/practitioners of the
290 healthcare service in order to properly care for patients?

291 Would you change the co-ordination of care in any way?

292

293 **Psychological Support:**

294

295 **Which aspects of a patient (with a chronic condition) condition/care do you believe**
296 **cause them anxiety?**

297 What causes anxiety and worry for you?

298

299 **To what extent do you believe psychological support should be available to**
300 **outpatients?**

301 - How are patients advised to support themselves in their condition?

302 - How do you ensure patients are supporting themselves?

303 - Do you provide psychological resources?

304

305 **Describe how you would improve psychological care for patients with chronic**
306 **illnesses?**

307

308 **Other Chronic Disease Models:**

309

310 **Can you describe any awareness you have of how other adults with chronic disease**
311 **manage their conditions, for example diabetes or cystic fibrosis?**

312 - Is this something that could work for adults with CHD?

313 - What problems do you foresee for adults with CHD?

314

315 **What is your opinion of patients with chronic illnesses self-managing their condition?**

316 - Which areas should stay under clinician control?

317

318 **Which emerging mobile health technologies might be suitable for use in adults with**
319 **CHD?**

320

321 **Is there anything we haven't discussed you believe to be important when thinking**
322 **about ACHD outpatient care?**

323

324