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Patient Survey – The Heart Hive COVID-19 Study
14th May 2020. Version 1.0

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1. **Do you have cardiomyopathy?**
   - o Yes
   - o No

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2. *Show if: CARDIOMYOPATHY= [Yes]*

   What type of cardiomyopathy have you been diagnosed with? *Please select one*
   - o DCM, Dilated Cardiomyopathy
   - o HCM, Hypertrophic Cardiomyopathy
   - o ACM/ARVC, Arrhythmogenic Cardiomyopathy or Arrhythmogenic Right Ventricular Cardiomyopathy
   - o LVNC, Left Ventricular Non-Compaction
   - o ICM, Ischaemic Cardiomyopathy
   - o RCM, Restrictive Cardiomyopathy
   - o Takotsubo (stress-related) Cardiomyopathy
   - o Peripartum cardiomyopathy
   - o Unknown or Undefined type
   - o Don't know
   - o Other

   Additional info:_____

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3. *Show if: CARDIOMYOPATHY = [No]*

   Which of the following best describes you? *Please select one*
   - o I do not have heart disease
   - o I do not have heart disease, but someone in my household has cardiomyopathy
   - o I have previously had myocarditis and I've been told that this has resolved
   - o Other _____

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4. **Please identify your sex from the list below.** *Please select one*
   - o Male
   - o Female
   - o Trans male (on hormone therapy)
   - o Trans female (on hormone therapy)

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5. **Which of the following best describes your ethnicity?** *Please select one*

   White
   - o English/Welsh/Scottish/Northern Irish/British
   - o Irish
   - o Gypsy or Irish traveller
   - o Non-Finnish European
   - o Finnish

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Mixed / multiple ethnic groups
- ○ White and Black Caribbean
- ○ White and Black African
- ○ Any other Mixed / Multiple ethnic background, please describe _____

Asian / Asian British
- ○ Indian
- ○ Pakistani
- ○ Bangladeshi
- ○ Chinese
- ○ Any other Asian, please describe _____

Black / African / Caribbean / Black British
- ○ African
- ○ Caribbean
- ○ Any other Black / African / Caribbean background, please describe _____

Arab
- ○ Arab
- ○ Any other Arab background, please describe _____

Americas
- ○ White American
- ○ American Indian or Alaska Native
- ○ Hispanic/Latino
- ○ Native Hawaiian or Other Pacific Islander
- ○ Other, please describe _____

Other ethnic group
- ○ Any other ethnic group, please describe _____

Prefer not to answer
- ○ I prefer not to answer

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6. *CORONA_STATUS*

Are you, or have you been, infected with coronavirus? *Please select one*
- ○ Yes, tested and the result was positive
- ○ Yes, suspected but not confirmed by a test
- ○ No, tested and the result was negative
- ○ No
- ○ Don't know

7. *Show if: CORONA_STATUS = [Yes, tested and the result was positive]*

a. **What was the date of your positive test?**
    If you can't recall the exact date, please give an approximate date

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b. What type of test for coronavirus did you have? *Please check all that apply*
- ☐ A throat swab test
- ☐ A blood test
- ☐ Other_____

c. Did you have symptoms of coronavirus? *Please select one*
- ○ Yes
- ○ No
- ○ Unsure

8. *Show if: CORONA_ SYMPTOMS = [Yes] & CORONA_STATUS = [Yes, suspected but not confirmed by a test]*

What was the date that you developed symptoms?
If you can't recall the exact date, please give an approximate date

9. *Show if: CORONA_STATUS = [Yes, tested and the result was positive] or [Yes, suspected but not confirmed by a test]*

Did you stay in hospital for one or more nights due to the coronavirus infection?   *Please select one*
- ○ Yes
- ○ No
- ○ Unsure

10. *Show if: HOSPITAL_STAY = [Yes]*

a. Were you admitted to intensive care due to coronavirus? *Please select one*
- ○ Yes
- ○ No
- ○ Unsure

b. Did you require a ventilator due to coronavirus? *Please select one*
- ○ Yes
- ○ No
- ○ Unsure

c. Did you have an ultrasound scan of your heart (echocardiogram) while you were in hospital? *Please select one*
- ○ Yes
- ○ No
- ○ Unsure

11. *Show if: CORONA_STATUS = [Yes] or [suspected but not confirmed by a test] and CORONA_TEST_SYMPTOMS = [Yes]*

a. Do you currently feel as though you have fully recovered from coronavirus? *Please select one*
- ○ Yes
- ○ No

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- o Unsure
- o Not applicable

b. Have your symptoms of coronavirus ever returned? *Please select one*
- o Yes
- o No
- o Unsure
- o Not applicable

12. **Since the beginning of the coronavirus pandemic, have you experienced any of the following symptoms?** *Please select one for each question*

   a. Loss of smell and taste
   - o Yes
   - o No
   - o Unsure

   b. Severe or significant persistent cough
   - o Yes
   - o No
   - o Unsure

   c. Severe fatigue
   - o Yes
   - o No
   - o Unsure

   d. Skipped meals
   - o Yes
   - o No
   - o Unsure

13. **Has anyone in your household been infected with coronavirus?** *Please select one*
- o Yes, confirmed with a test
- o Yes, suspected but not confirmed by a test
- o No, tested and the result was negative
- o No
- o Don't know
- o Not applicable

14. *Show if:* HOUSEHOLD_INFECTION= *[Yes, confirmed with a test]*

What was the date of your household member's positive test?
If you can't recall the exact date, please give an approximate date

15. *Show if* HOUSEHOLD_INFECTION= *[Yes, suspected but not confirmed by a test]*

What was the date that your household member developed symptoms?
If you can't recall the exact date, please give an approximate date

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16. Show if: CORONA_STATUS= [No, tested and the result was negative], [No], [Don't know]

a. What do you consider to be your own probability of getting infected with coronavirus? *Please select one*
Extremely unlikely [*] [*] [*] [*] [*] [*] Extremely likely

b. How susceptible do you consider yourself to an infection with coronavirus? *Please select one*
Not at all susceptible [*] [*] [*] [*] [*] [*] [*] Very susceptible

c. How severe do you think contracting coronavirus would be for you (how seriously ill do you think you will be)? *Please select one*
Not severe [*] [*] [*] [*] [*] [*] [*] Very severe

17. Show if: CORONA_STATUS= [Yes, tested and the result was positive], [Yes, suspected but not confirmed by a test]

a. Before you developed coronavirus, what did you consider to be your own probability of getting infected? *Please select one*
Extremely unlikely [*] [*] [*] [*] [*] [*] [*] Extremely likely

b. How susceptible did you consider yourself to an infection with coronavirus? *Please select one*
Not at all susceptible [*] [*] [*] [*] [*] [*] [*] Very susceptible

c. How severe did you think coronavirus would be for you? *Please select one*
Not severe [*] [*] [*] [*] [*] [*] [*] Very severe

18. Some people with one of a number of different medical conditions have received specific advice about avoiding face to face contact with others. We are interested in knowing more about what advice has been given to subjects in this study.

a. Have you ever been advised to avoid all face-face contact with other people (shielding)? *Please select one*
- o Yes
- o No
- o Don't know

b. Are you currently avoiding all face-face contact with other people (shielding)? *Please select one*
- o Yes
- o No
- o Don't know

19. Show if: SHIELDING_ADVISED= [Yes]

a. Which health condition resulted in the recommendation from your healthcare provider to avoid all face-face contact (shielding)? _____

b. Have you previously received a heart transplant?

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o   Yes
o   No

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20. *Show if: SHIELDING_ADVISED= [No] and SHIELDING_PRACTICED = [Yes]*

a. Which health condition resulted in your decision to avoid all face-face contact (shielding)?
_____

b. Have you previously received a heart transplant?
o   Yes
o   No

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21. *Show if: CORONA_STATUS = [No, tested and the result was negative]; [No]; [Don't know]*

a. "I know how to protect myself from coronavirus." *Please select one*
Not at all [*] [*] [*] [*] [*] [*] [*] Very much so

b. "For me avoiding an infection with coronavirus in the current situation is…" *Please select one*
Extremely difficult [*] [*] [*] [*] [*] [*] [*] Extremely easy

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22. *Show if: CORONA_STATUS = [Yes, tested and the result was positive]; [Yes, suspected but not confirmed by a test]*

a. "I felt I knew how to protect myself from coronavirus." *Please select one*
Not at all [*] [*] [*] [*] [*] [*] [*] Very much so

b. "Avoiding an infection with coronavirus in the current situation would have been…" *Please select one*
Extremely difficult [*] [*] [*] [*] [*] [*] [*] Extremely easy

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23.

a. "I have been able to access sufficient information to understand what I need to do to reduce my chances of contracting coronavirus." *Please select one*
Strongly disagree [*] [*] [*] [*] [*] [*] [*] Strongly agree

b. Where have you looked for information on how coronavirus may affect you? *Please check all that apply*
☐   Search engines (e.g. Google)
☐   NHS/government website
☐   British Heart Foundation website
☐   Cardiomyopathy UK website
☐   Other websites
☐   Social media
☐   From my GP
☐   From my hospital
☐   Other
☐   I have not looked for information on this

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Additional info _____

24.

a. "At the moment, I am following the current national/state recommendations on when I can leave the house." *Please select one*
- ○ True
- ○ False
- ○ Unsure
- ○ Not applicable

b. "In the past, I have followed recommendations about when I can leave the house at all times." *Please select one*
- ○ True
- ○ False
- ○ Unsure
- ○ Not applicable

c. "I have changed my working arrangements due to the coronavirus pandemic." *Please select one*
- ○ True
- ○ False
- ○ Unsure
- ○ Not applicable

d. "I am currently not working as a result of the coronavirus pandemic." *Please select one*
- ○ True
- ○ False
- ○ Unsure
- ○ Not applicable

25.

For each of the statements below please choose one option per row that best describes you.

"Coronavirus to me feels..." *Please select one for each*
- a) Stressful [*] [*] [*] [*] [*] [*] [*] Not stressful
- b) Fear-inducing [*] [*] [*] [*] [*] [*] [*] Not fear-inducing
- c) Worrying [*] [*] [*] [*] [*] [*] [*] Not worrying
- d) Media hyped [*] [*] [*] [*] [*] [*] [*] Not media hyped
- e) Something I think about all the time [*] [*] [*] [*] [*] [*] [*] Something I almost never think about
- f) Something that makes me feel helpless [*] [*] [*] [*] [*] [*] [*] Something I am able to combat with my own action
- g) Something that is making me depressed [*] [*] [*] [*] [*] [*] [*] Something that does not affect my mood

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26.

a. "I feel that my physical health has suffered as a result of the coronavirus pandemic." *Please select one*

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- o True
- o False
- o Unsure

b. "If I started to feel extremely unwell, I would…" *Please select one*
- o Attend hospital
- o Be very reluctant to attend hospital
- o Never attend hospital

c. "Attending hospital in the midst of the coronavirus pandemic would make me…" *Please select one*

   Very worried [*] [*] [*] [*] [*] [*] [*] Not worried at all

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27. *Show if: CARDIOMYOPATHY = [yes]*

a. "I have had a cardiology clinic appointment changed to a telephone consultation due to the coronavirus pandemic." *Please select one*
- o True
- o False
- o Unsure
- o Not applicable

b. "I have had a cardiology clinic appointment re-scheduled to a later date due to the coronavirus pandemic." *Please select one*
- o True
- o False
- o Unsure
- o Not applicable

c. "I have had a cardiology clinic appointment cancelled due to the coronavirus pandemic and this has not been rescheduled." *Please select one*
- o True
- o False
- o Unsure
- o Not applicable

d. "I have run out of, or missed doses of, my medications due to the coronavirus pandemic." *Please select one*
- o True
- o False
- o Unsure
- o Not applicable

e. "I have missed out on tests or investigations due to the coronavirus pandemic (e.g. heart scans, heart rhythm recordings, invasive tests etc)." *Please select one*
- o True – I have missed out on tests because they were postponed or cancelled
- o True – I have missed out on tests because I could not leave the house due to coronavirus
- o False
- o Unsure
- o Not applicable

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f. "A planned procedure relating to my heart was delayed or cancelled as a result of the coronavirus pandemic." *Please select one*
- o   True
- o   False
- o   Unsure
- o   Not applicable

g. "I imagine that my usual cardiology service is…." *Please select one*
- o   Currently providing a full service and not affected by the coronavirus pandemic
- o   Currently providing reduced service due to coronavirus
- o   Currently shut down due to coronavirus
- o   Unsure

h. "I feel satisfied that my healthcare needs can be met through remote or telephone consultations." *Please select one*
- o   True
- o   False
- o   Unsure
- o   Not applicable

28. *Show if: CARDIOMYOPATHY= [yes]*

a. "I feel that symptoms from my heart condition have got worse as a result of the coronavirus pandemic." *Please select one*

- o   True
- o   False
- o   Unsure

b. "If symptoms related to my heart condition got worse, I would know what to do." *Please select one*
Strongly disagree [*] [*] [*] [*] [*] [*] [*] Strongly agree

c. "If symptoms related to my heart condition got significantly worse, I would…" *Please select one*
- o   Attend hospital
- o   Be very reluctant to attend hospital
- o   Never attend hospital

d. "I feel confident that I could distinguish symptoms related to my heart condition from symptoms caused by a coronavirus infection." *Please select one*

- o   True
- o   False
- o   Unsure

29.

Is there anything else that you would like to add?_____

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