NWU® | Human Metabolomics

CONSENT FROM THE PARENTS

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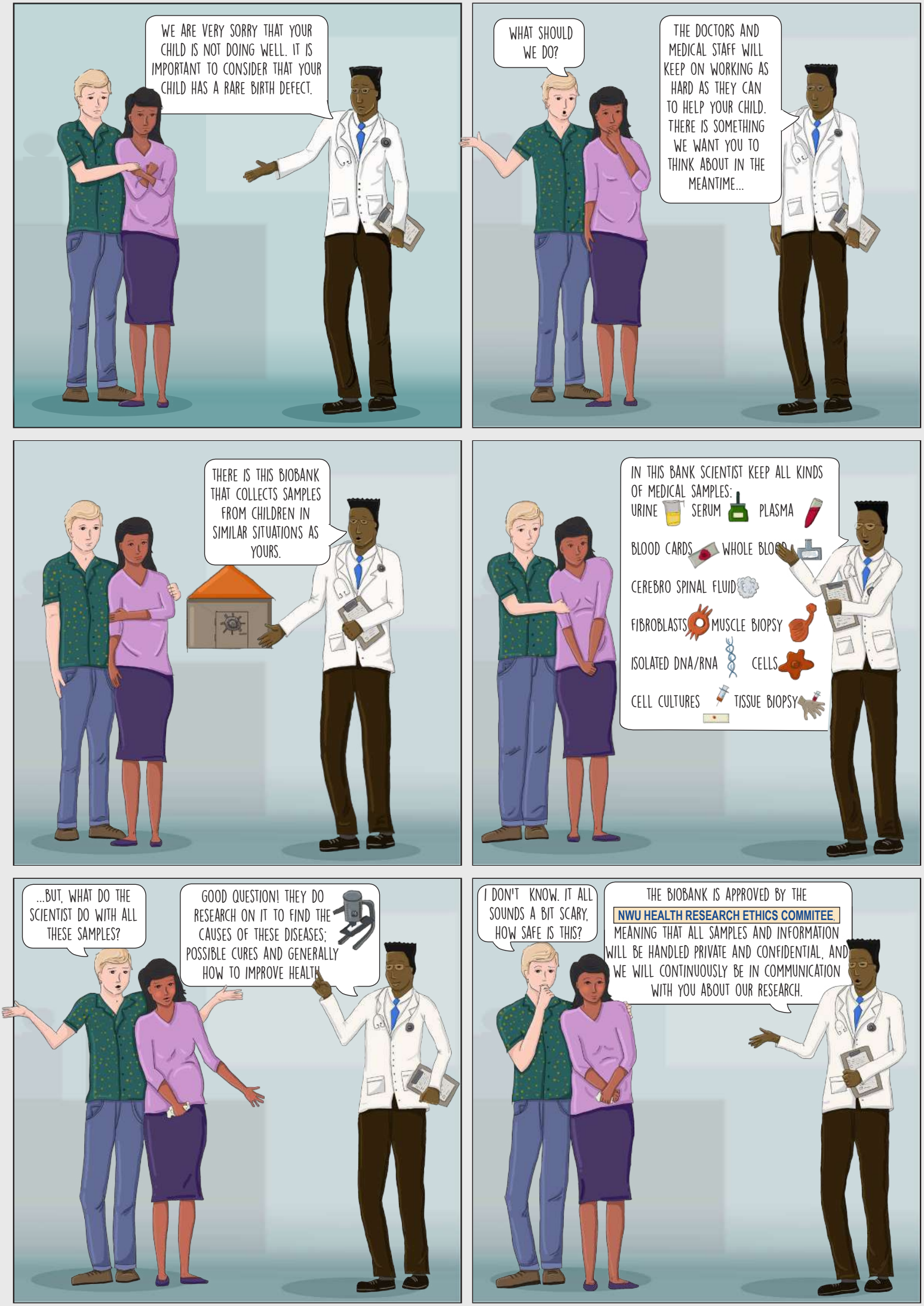
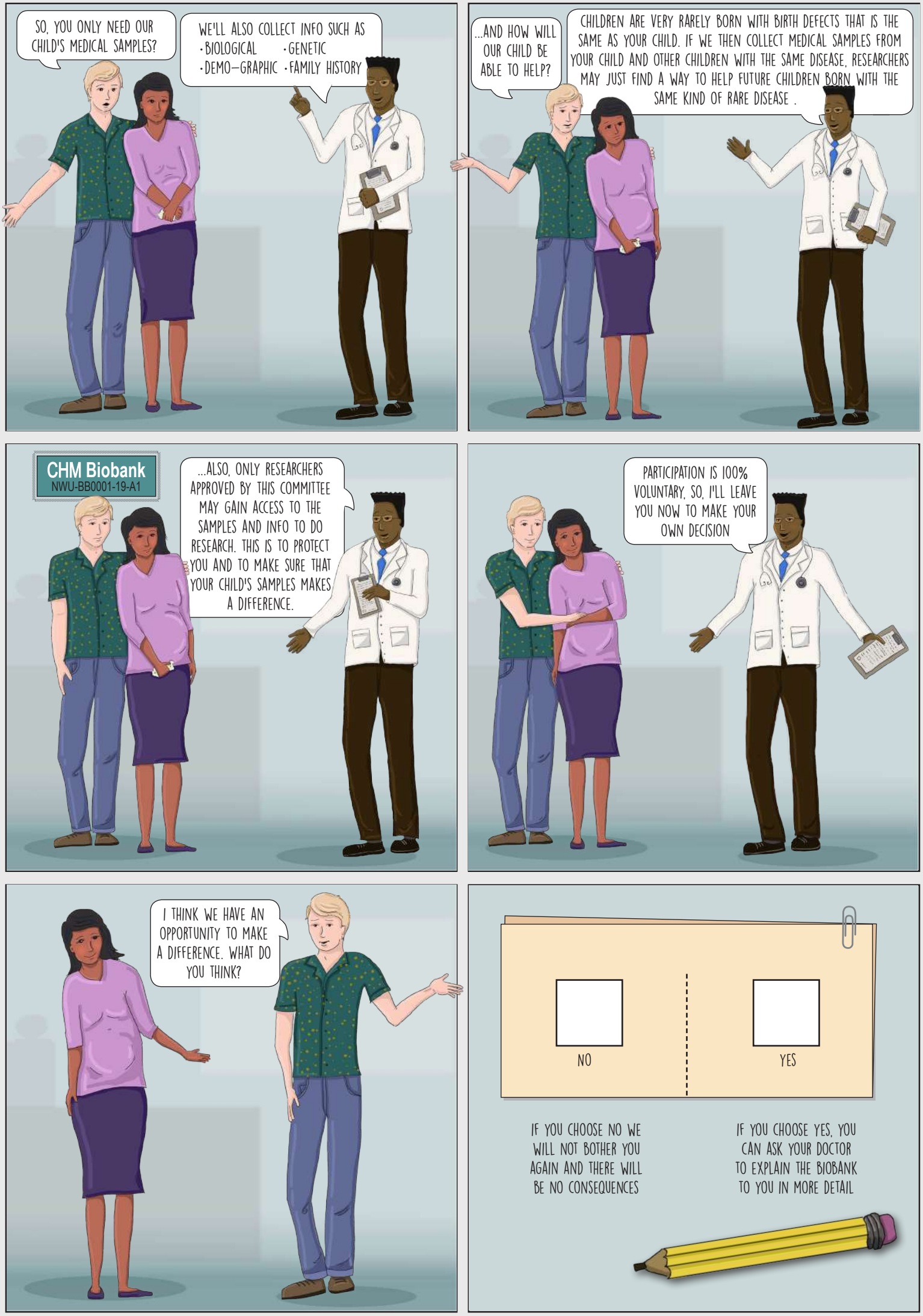

WE ARE VERY SORRY THAT YOUR CHILD IS NOT DOING WELL. IT IS IMPORTANT TO CONSIDER THAT YOUR CHILD HAS A RARE BIRTH DEFECT.
WHAT SHOULD WE DO?
THE DOCTORS AND MEDICAL STAFF WILL KEEP ON WORKING AS HARD AS THEY CAN TO HELP YOUR CHILD. THERE IS SOMETHING WE WANT YOU TO THINK ABOUT IN THE MEANTIME...
THERE IS THIS BIOBANK THAT COLLECTS SAMPLES FROM CHILDREN IN SIMILAR SITUATIONS AS YOURS.
IN THIS BANK SCIENTIST KEEP ALL KINDS OF MEDICAL SAMPLES:
URINE
SERUM
PLASMA
BLOOD CARDS
WHOLE BLOOD
CEREBRO SPINAL FLUID
FIBROBLASTS
MUSCLE BIOPSY
ISOLATED DNA/RNA
CELLS
CELL CULTURES
TISSUE BIOPSY
...BUT, WHAT DO THE SCIENTIST DO WITH ALL THESE SAMPLES?
GOOD QUESTION! THEY DO RESEARCH ON IT TO FIND THE CAUSES OF THESE DISEASES; POSSIBLE CURES AND GENERALLY HOW TO IMPROVE HEALTH
I DON'T KNOW. IT ALL SOUNDS A BIT SCARY, HOW SAFE IS THIS?
THE BIOBANK IS APPROVED BY THE NWU HEALTH RESEARCH ETHICS COMMITEE, MEANING THAT ALL SAMPLES AND INFORMATION WILL BE HANDLED PRIVATE AND CONFIDENTIAL, AND WE WILL CONTINUOUSLY BE IN COMMUNICATION WITH YOU ABOUT OUR RESEARCH.


SO, YOU ONLY NEED OUR CHILD'S MEDICAL SAMPLES?
WE'LL ALSO COLLECT INFO SUCH AS
·BIOLOGICAL ·GENETIC
·DEMO–GRAPHIC ·FAMILY HISTORY
...AND HOW WILL OUR CHILD BE ABLE TO HELP?
CHILDREN ARE VERY RARELY BORN WITH BIRTH DEFECTS THAT IS THE SAME AS YOUR CHILD. IF WE THEN COLLECT MEDICAL SAMPLES FROM YOUR CHILD AND OTHER CHILDREN WITH THE SAME DISEASE, RESEARCHERS MAY JUST FIND A WAY TO HELP FUTURE CHILDREN BORN WITH THE SAME KIND OF RARE DISEASE .
CHM Biobank
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...ALSO, ONLY RESEARCHERS APPROVED BY THIS COMMITTEE MAY GAIN ACCESS TO THE SAMPLES AND INFO TO DO RESEARCH. THIS IS TO PROTECT YOU AND TO MAKE SURE THAT YOUR CHILD'S SAMPLES MAKES A DIFFERENCE.
PARTICIPATION IS 100% VOLUNTARY, SO, I'LL LEAVE YOU NOW TO MAKE YOUR OWN DECISION
I THINK WE HAVE AN OPPORTUNITY TO MAKE A DIFFERENCE. WHAT DO YOU THINK?
NO
YES
IF YOU CHOOSE NO WE WILL NOT BOTHER YOU AGAIN AND THERE WILL BE NO CONSEQUENCES
IF YOU CHOOSE YES, YOU CAN ASK YOUR DOCTOR TO EXPLAIN THE BIOBANK TO YOU IN MORE DETAIL