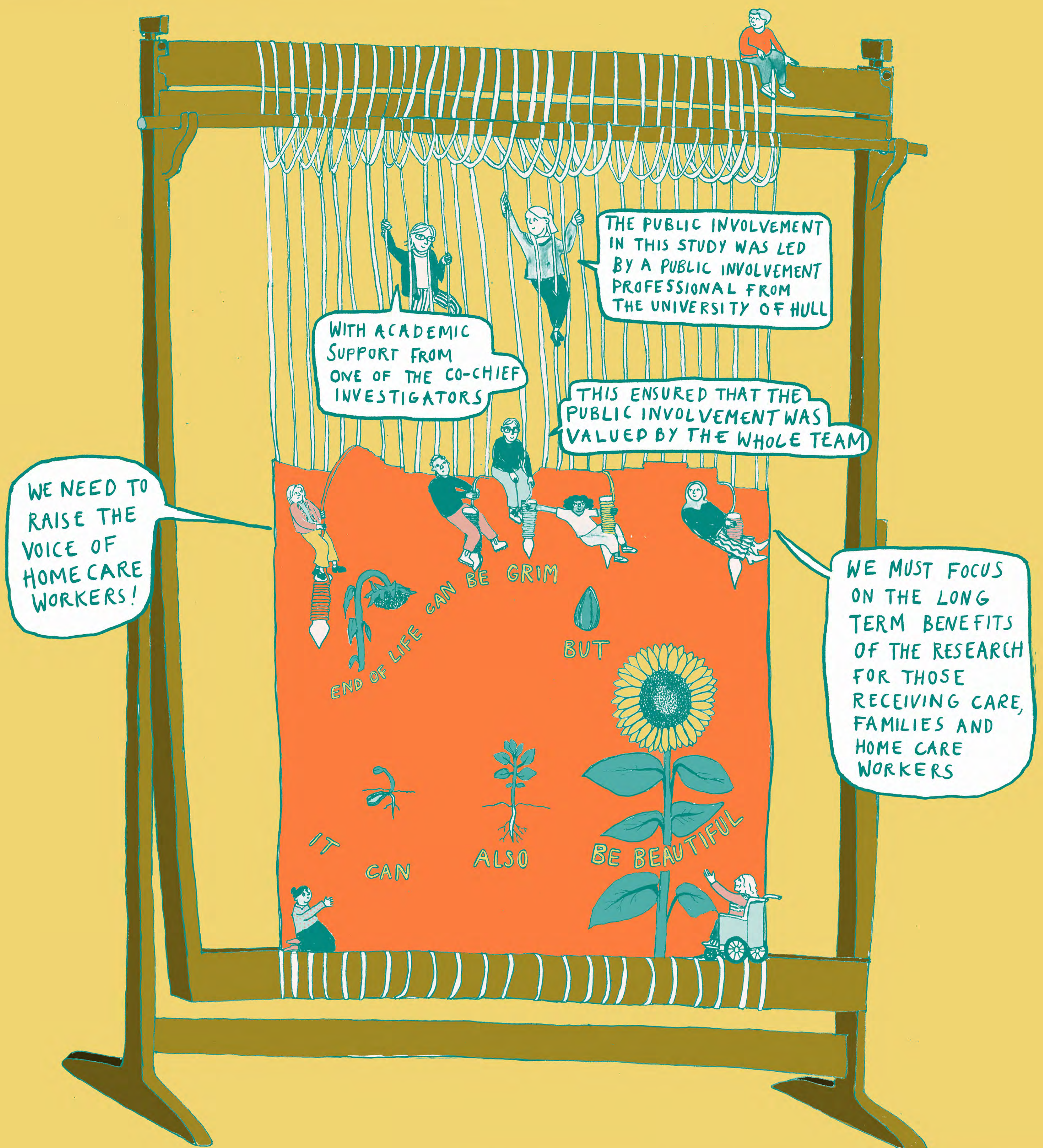


This comic describes the public involvement in the SUPPORTED study
about homecare work at end-of-life

THIS PROJECT INVOLVED MANY PEOPLE
FROM DIFFERENT BACKGROUNDS COMING
TOGETHER TO ADVISE THE RESEARCH TEAM



OUR DIFFERENT EXPERIENCES WOVE
TOGETHER TO CREATE BETTER, RICHER
RESEARCH INFORMED BY REAL PEOPLE
AND THEIR LIFE EXPERIENCES

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SUPPORTED

WHAT DID WE WANT TO FIND OUT?

SOME WILL SAY I'M JUST A CARER, BUT I AM THE GLUE THAT HOLDS IT ALL TOGETHER

HOME CARE WORKERS ARE AN UNDERVALUED BUT ESSENTIAL PART OF THE HEALTH CARE SYSTEM IN ENGLAND

WE PROVIDE CARE FOR PEOPLE NEARING THE END OF LIFE, BUT THE TRAINING + SUPPORT WE RECEIVE IS OFTEN POOR

LITTLE IS KNOWN ABOUT THE EXPERIENCES OF HOME CARE WORKERS OR THEIR TRAINING AND SUPPORT NEEDS

WE CARRIED OUT THE SUPPORTED STUDY TO FILL THIS GAP

WHAT DID WE DO?

THROUGH INTERVIEWS WE EXPLORED THE EXPERIENCES + TRAINING NEEDS OF HOME CARE WORKERS FROM DIFFERENT PERSPECTIVES

WE ALSO REVIEWED POLICY DOCUMENTS AND EXISTING TRAINING PROVISION

WE CO-DESIGNED A RANGE OF NEW TRAINING RESOURCES AND DEVELOPED RECOMMENDATIONS FOR A COMMUNITY OF PRACTICE

THE STUDY TOOK PLACE IN: BRADFORD HULL BROMLEY

OUR STUDY INCLUDED AN AMBITIOUS PLAN FOR PUBLIC INVOLVEMENT

WHY DID WE INVOLVE PEOPLE?

INVITE MANY VOICES TO THE TABLE, CREATE MULTIPLE TABLES TO HELP DIFFERENT VOICES BE HEARD

IT WAS IMPORTANT TO US TO INVOLVE A MIXTURE OF PEOPLE FROM ALL 3 PLACES

WE WANTED TO INCLUDE PEOPLE WITH PERSONAL EXPERIENCE OF RECEIVING OR PROVIDING HOME CARE TOWARD THE END OF LIFE

INCLUDING THOSE LIVING WITH ADVANCED ILLNESS AND UNPAID CARERS FOR A FAMILY MEMBER OR FRIEND

WHO DID WE INVOLVE

WE SELECTED PEOPLE WITH DIFFERENT EXPERIENCES, A PERSON'S EXPERIENCES MIGHT BE INFLUENCED BY:

- AGE
- ETHNICITY
- CULTURE
- FAMILY
- GENDER
- EDUCATION
- LOCATION

WE COMMITTED TO INVOLVING PEOPLE THROUGHOUT THE STUDY

IN ORDER TO BUILD RELATIONSHIPS + UNDERSTANDING

SERVICE USER + CARER ADVISORY GROUP

HOME CARE WORKER ADVISORY GROUP

STUDY MANAGEMENT GROUP

STEERING COMMITTEE

THE WAY WE SEE IS AFFECTED BY WHAT WE KNOW OR WHAT WE BELIEVE... WE ONLY SEE WHAT WE LOOK AT TO LOOK IS AN ACT OF CHOICE (JOHN BERGER)

IN THIS STUDY WE CHOSE TO SEE HOME CARE WORKERS, BRINGING DIFFERENT WAYS OF KNOWING INTO THE RESEARCH PROCESS

THE HEALTH + CARE WORKFORCE ARE OFTEN EXCLUDED FROM PUBLIC INVOLVEMENT BECAUSE WE ARE SEEN AS HAVING A "PROFESSIONAL" RATHER THAN "PUBLIC" PERSPECTIVE

INSTEAD WE WANTED TO BE PRAGMATIC + FOCUS ON THE BENEFITS OF INVOLVING THEM

WE ARE A WORKFORCE WHOSE OPINIONS ARE RARELY ASKED FOR + WITH VERY LITTLE INFLUENCE ON DECISION MAKING IN OUR WORKING LIVES

WE WANTED OUR PUBLIC INVOLVEMENT TO MIRROR THE FOCUS OF THE STUDY + ACTIVELY LISTEN TO HOME CARE WORKERS

WE ASKED OUR HOME CARE WORKER ADVISORS TO REFLECT ON THEIR INVOLVEMENT TOWARDS THE END OF THE PROJECT

AMONG THOSE WE INVOLVED SOME PEOPLE WERE WEARING MANY DIFFERENT HATS

I WAS VERY NERVOUS ABOUT HAVING CONVERSATIONS WITH ACADEMICS, I LEFT SCHOOL WITHOUT ANY QUALIFICATION

I HAVE A UNIVERSITY EDUCATION BUT I WAS NERVOUS ABOUT TALKING TO ACADEMICS IN ENGLISH AS IT'S NOT MY FIRST LANGUAGE

BUT WE ALL FELT RESPECTED + LISTENED TO BY THE RESEARCH TEAM

I SOON FELT COMFORTABLE

THIS MADE THEM UNCERTAIN ABOUT BEING PART OF A PARTICULAR GROUP WHICH HAT SHOULD THEY WEAR?

OVERLAPPING EXPERIENCES ARE JUST PART OF REAL LIFE!

WE ENCOURAGED PEOPLE TO REFLECT FROM WHICHEVER PERSPECTIVE SEEMED MOST USEFUL AT THE TIME

HOME CARE WORKER RECEIVED HOME CARE FOR A PARENT! ARRANGED HOME CARE FOR MYSELF

HOW DID WE INVOLVE PEOPLE?

WELCOME! RESEARCHERS ATTENDED THE GROUP MEETINGS IN SMALL NUMBERS

IN BETWEEN MEETINGS WE PRODUCED REGULAR NEWSLETTERS

MEETINGS WERE HOSTED BY THE PUBLIC INVOLVEMENT CO-ORDINATOR, SO THAT THE SPACES FELT COMFORTABLE AND FRIENDLY

WE HELD WELCOME MEETINGS FOR EACH GROUP TO HELP US GET TO KNOW EACH OTHER. THIS WELCOMING APPROACH WAS REPEATED EACH TIME A GROUP MET + AS NEW MEMBERS JOINED

WE TRIED TO WRITE IN PLAIN ENGLISH AND DISCUSS OUR WORK WITHOUT JARGON

WE ARRANGED OUR MEETINGS TO SUIT MEMBERS OF THE GROUPS

INVOLVING THE HOME CARE WORKER GROUP WAS NOT EASY, ONE MEMBER OF THE GROUP DISENGAGED AT A VERY EARLY STAGE

MOST EXPERIENCED HOME CARE WORKER

THE CONSENT FORM MIGHT PUT HOME CARE WORKERS OFF TAKING PART, THEY MIGHT WORRY ABOUT WHAT WOULD HAPPEN IF THEY TALKED ABOUT POOR PRACTICE OR SAFEGUARDING ISSUES

THE PUBLIC INVOLVEMENT CO-ORDINATOR SUPPORTED ALL THOSE INVOLVED IN THE STUDY

I OFFERED REGULAR SMALL GROUP OR ONE TO ONE CONVERSATIONS TO HELP THEM PREPARE FOR MEETINGS + ADDRESS ANY CONCERNS

I ALSO ORGANISED ONLINE LEARNING EVENTS + CREATED LEARNING GUIDES

WE COLLECTED DETAILED EVIDENCE OF THE DIFFERENCE THAT PUBLIC INVOLVEMENT MADE TO THE RESEARCH, THE RESEARCHERS + THE PEOPLE WE INVOLVED

WHAT DID WE DO AND WHAT DID WE LEARN?

THE GROUP HELPED US DECIDE HOW TO APPROACH THE INTERVIEWS

CAN YOU SHARE SUPPORT INFORMATION AFTER THE INTERVIEW? PEOPLE MIGHT FEEL UPSET AFTER SHARING THEIR EXPERIENCES

BUT MAYBE DON'T MENTION BEREAVEMENT SUPPORT, SOME PEOPLE DON'T KNOW THEIR LOVED ONE IS NEARING THE END OF LIFE

IT'S A GREAT IDEA TO ASK PEOPLE TO DESCRIBE THEIR IDEAL HOME CARE WORKER

THEY ALSO HELPED US WITH THE INTERVIEW QUESTIONS

WE DID NOT RECEIVE ETHICAL APPROVAL FOR THE INTERVIEWS UNTIL WE RECONSIDERED OUR USE OF LANGUAGE TO DESCRIBE END OF LIFE

OUR PUBLIC CONTRIBUTORS HELPED US AGREE ON 'PEOPLE LIVING WITH ADVANCED ILLNESS'

WE TALKED TO THE GROUPS ABOUT RECRUITING PARTICIPANTS FOR INTERVIEW

HOW CAN WE FIND MORE PEOPLE AND PERSUADE THEM TO TAKE PART?

PARTICULARLY FROM UNDER REPRESENTED COMMUNITIES

DURING THE INTERVIEWS THE RESEARCHERS PRESENTED THEIR EARLY FINDINGS TO THE GROUP

... THIS IS WHAT WE'VE FOUND OUT SO FAR DOES THIS MAKE SENSE? IS IT IN LINE WITH YOUR EXPERIENCE?

WE REPEATED THIS PROCESS 6 MONTHS LATER WHEN THE INTERVIEWS WERE COMPLETE

THE HOME CARE WORKER GROUP INFLUENCED OUR APPROACH TO THE CO-DESIGN PROCESS

RUN SEPARATE WORKSHOPS FOR HOME CARE WORKERS + MANAGERS SO WORKERS CAN SPEAK MORE FREELY

OFFER A MIXTURE OF ONLINE + IN PERSON WORKSHOPS

AND MAKE SURE YOU TALK THEM TO AVOID SHIFT HANDOVERS + PEAK TIMES IN A HOME CARE WORKER'S DAY

AND FIX THE DATES ABOUT A MONTH IN ADVANCE

WE USED THEIR ADVICE TO PLAN OUR WORKSHOPS

AS WE DEVELOPED TRAINING RESOURCES PEOPLE HELPED US MAKE SOME IMPORTANT DECISIONS

FOR THE TRAINING SLIDES WE THOUGHT WE COULD USE DIGITALLY GENERATED VOICE OR ONE OF THE RESEARCHERS COULD NARRATE?

I DON'T THINK EITHER OF THOSE WOULD WORK

IT NEEDS TO BE A VOICE THAT SOUNDS APPROACHABLE AND ONE THAT IS CLEAR + UNDERSTANDABLE IF ENGLISH ISN'T YOUR FIRST LANGUAGE

AS A RESULT WE CHOSE TO USE A PROFESSIONAL VOICEOVER ARTIST

PEOPLE SHARED IDEAS FOR HOW THE TRAINING RESOURCES MIGHT BE USED IN PRACTICE

HOME CARE WORKERS COULD USE THE 'WHAT IF...' CARDS TO HELP MAKE DECISIONS IN DIFFICULT SITUATIONS + MANAGERS COULD CREATE A TRAINING SESSION USING THE CARDS

THEY GAVE ADVICE ABOUT SPECIFIC TRAINING TOPICS INCLUDING RESPONDING TO THE CULTURAL + RELIGIOUS NEEDS OF PEOPLE AT THE END OF LIFE

THEY HELPED US TO IMPROVE THE TONE + LANGUAGE USED IN THE RESOURCES

RELATIONSHIPS & SUPPORT

IT WAS HELPFUL TO HAVE SOMEONE ON THE RESEARCH TEAM WHOSE SPECIFIC ROLE WAS TO CO-ORDINATE THE PUBLIC INVOLVEMENT + SUPPORT THOSE INVOLVED

IT WAS BENEFICIAL FOR THIS PERSON TO SIT BETWEEN THE RESEARCHERS + THE PUBLIC + TO NOT BE A RESEARCHER THEMSELVES

WHAT WE ASK OF THOSE INVOLVED IN RESEARCH IS HARD. IT REQUIRES AN ABILITY TO SHARE THEIR PERSONAL EXPERIENCES, BUT NOT IN TOO MUCH DETAIL, + IN DOING SO REFLECT ON WHAT THAT MIGHT MEAN FOR SOMETHING AS TECHNICAL + CONTROLLED AS AN ACADEMIC RESEARCH PROJECT. SOME REVISITED DISTRESSING EXPERIENCE IN OUR MEETINGS + WERE LEFT WITH THESE FEELINGS AFTERWARDS. WE TRIED TO MITIGATE AGAINST THIS BY DEVELOPING OPEN SUPPORTIVE RELATIONSHIPS

REFLECTIONS

WE WEREN'T JUST A NUMBER... WE WERE PEOPLE... I HAD A VOICE + WHAT I HAD TO SAY WAS IMPORTANT

AN ACADEMIC RESEARCH PROJECT TAKES TIME + THIS RESULTED IN SOME FRUSTRATION IN THE EARLY STAGES

YOU SPEAK ABOUT THE METHODS IN HUGE DETAIL BUT WHAT IS THE GOAL? YOU DO NOT HIGHLIGHT WHAT YOU ARE HOPING TO ACHIEVE

THERE WAS A TENSION BETWEEN THE RESEARCH TEAM'S FOCUS ON THE RIGOUR OF THE RESEARCH PROCESS + THE QUALITY OF THE EVIDENCE

AND THAT OF THE PUBLIC CONTRIBUTORS, WHO WANTED TO IMPROVE CARE + IMPROVE HOW HOME CARE WORKERS ARE TREATED, IF POSSIBLE!

PUBLIC INVOLVEMENT IN THIS STUDY FOCUSED OUR MINDS ON THE LONG TERM AIMS + BENEFITS OF THE RESEARCH FOR THOSE RECEIVING CARE, FAMILIES + HOME CARE WORKERS

AND ITS POTENTIAL INFLUENCE ON POLICY + PRACTICE

THROUGHOUT THE RESEARCH PROCESS THIS WAS THE MAIN CONCERN OF MOST OF OUR PUBLIC CONTRIBUTORS

AND THEIR ENTHUSIASTIC SUPPORT HAD A POSITIVE INFLUENCE ON HOW WE MOVED FORWARD + DEALT WITH ISSUES ALONG THE WAY