# Patient perspectives and experiences of HIFU

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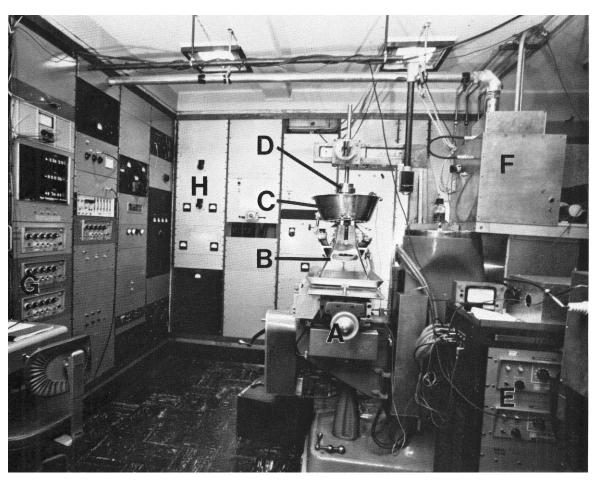


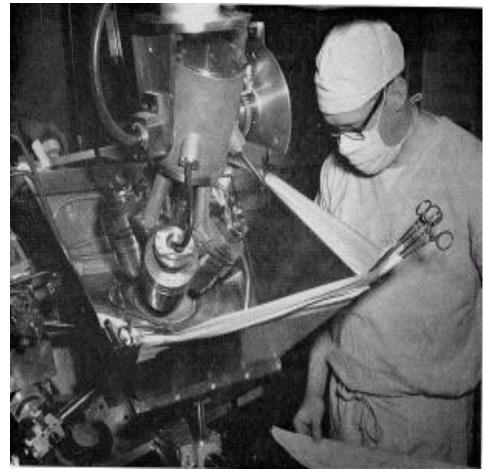
## Why HIFU?

• Surgery combined with chemotherapy is the current gold standard but it does not come without serious quality of life implications.

 HIFU is non invasive: patients tend to be back home after 48 hours in hospital in the same condition that they were previous to treatment

## History of HIFU





#### Patient referral

- This study is not widely known about
- We aim to treat anyone who is eligible
- Local: through our MDT
- National: individuals who are aware may refer
- Self referral by patients/relatives who have found the study themselves
- USA: contact vis the FUSF

#### First contact

- The only way to determine eligibility is by HIFU consultants reviewing imaging.
- Once Professor Wu has seen the scans and has confirmed that HIFU may be possible, I like to talk with the patient and then send the information sheet.
- People have a lot of questions at this point, but I try not to overwhelm them with information that may prove irrelevant.
- Organise a planning session

## Planning session

- Normal abdominal USS with Prof Wu in attendance
- Followed by a planning session on the same HIFU machine that delivers treatment.
- Can be uncomfortable due to the water bath and lying prone for a period of time
- Only then do we know for certain if HIFU is possible
- Or not which is very disappointing

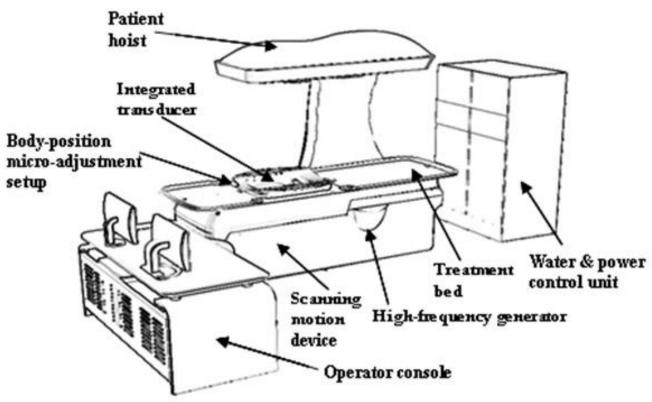
## US and HIFU machines





#### HIFU machine





## Patient pathway

- If they choose to take part there are a number of steps.
- Usually another scan
- Pre operative assessment
- Immune monitoring blood samples
- Organising for a couple of nights in hospital

## Discussion about the study

- Only then do I feel it is appropriate to have the detailed discussion about the study and if the patient would like to join.
- People have many questions and are in very different situations
- They often ask about the benefit
- Also the risks
- The time commitment and travel is also important

## Advantages and limitations

Non-invasive, Conformal ablation One session but repeatable No absolute limitation of tumor size Lower complications Short hospital stay No risk of increased metastasis, Potentially curative or palliative Enhanced antitumour immunity

Long time required
Skin Toxicity
Contraindications:
Lung, stomach
bowel

Treatment complexity

## On the day

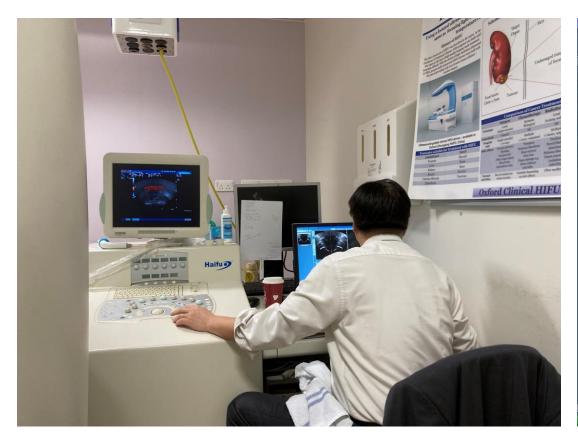
- Admitted to radiology day case unit
- Consent to procedure and trial
- QoL questionnaires
- Meet the anaesthetist
- Go to HIFU room
- Anaesthetic
- Positioning
- Treatment
- Recovery
- Ward

### HIFU treatment





#### HIFU treatment





## Hospital stay

- Usually 48 hours
- Then home with no restrictions
- I speak with them that evening and the next couple of days

## Follow up

- At two weeks post treatment for MRI and immune monitoring bloods
- I have a follow up call with them to explain the scan results and do QoL questionnaires
- End of study
- But I always stay in touch!

#### Patient characteristics

- Incredibly diverse group of patients screened and treated
- Youngest treated was 53 and the oldest was 80
- Varying stages of disease
- Some with metastatic disease
- All had chemotherapy, but at different points
- Some had immunotherapy
- Asymptomatic, fit and well
- Frail and deconditioned

- In a great deal of pain prior to treatment
- Woke up saying he felt better
- Was back gardening by the end of the week

- Felt the same on discharge as admission
- Said she was "very lucky indeed" to have had the treatment
- Went back to her book club a week after treatment

- Always said that she felt she was joining in to make a difference to those in the future
- Deteriorated after treatment
- Died 2 months later
- Keaton and I were honoured to be invited to her funeral where the family asked us to give a short talk

- Felt "better" after treatment
- Then had a few admissions due to unrelated complications in a local hospital
- Struggled emotionally and my feeling is that she felt the HIFU had created the problems not the disease

- Family found us through online searching
- Was a nurse and in a family of medics so very well informed
- Keen to do "anything she could"
- Tolerated treatment well
- Home to Devon
- Kept in touch and doing well

• "I completed the research programme this year. At all times I was met with respect, empathy and honesty regarding the aims of the programme. I had access to Katy via telephone at all times. I had 90% ablation of my primary cancer demonstrating that the programme cared for my needs as well as demonstrating the safety of the technique. It has helped me knowing that by taking part I may help future patients access far superior treatment and success rated than is available for pancreatic cancer today. It is worth taking part for this reason alone. I have nothing but praise for the team"

#### The future

- This study is drawing to a close and we are truly grateful for the time that people have given to join in and support friends or family on the study.
- It has laid down a base on which to build further options for patients with pancreatic cancer.
- It is rewarding to be able to offer someone an option that is relatively low risk when they may be limited with other choices