Internet-guided self-help for communities: Socioscientific challenges

Arise now in UK as national regulatory body (NICE):

  1. recognises efficacy and cost-effectiveness of computer-aided CBT (CCBT)

  2. recommends rapid implementation nationally

 3. Dept. of Health is supporting that implementation

9 outcome studies of *FearFighter*

- <u>Early</u>: on standalone computer in a clinic + brief support face-to-face from a therapist
  - -3 open studies *(Shaw et al 1999; Kenwright et al 2001, Marks et al 2003)*
  - -1 RCT *(Marks et al 2004)*
  - -[2 RCTs education *(McDonough & Marks 2002; Gega et al 2005)*]

- <u>Later</u>: on **internet** at home + brief support by helpline, email or MSN
  - -2 open studies *(Kenwright et al 2004; Scottish Highlands study 2006)*
  - -1 RCT *(Schneider et al 2005)*
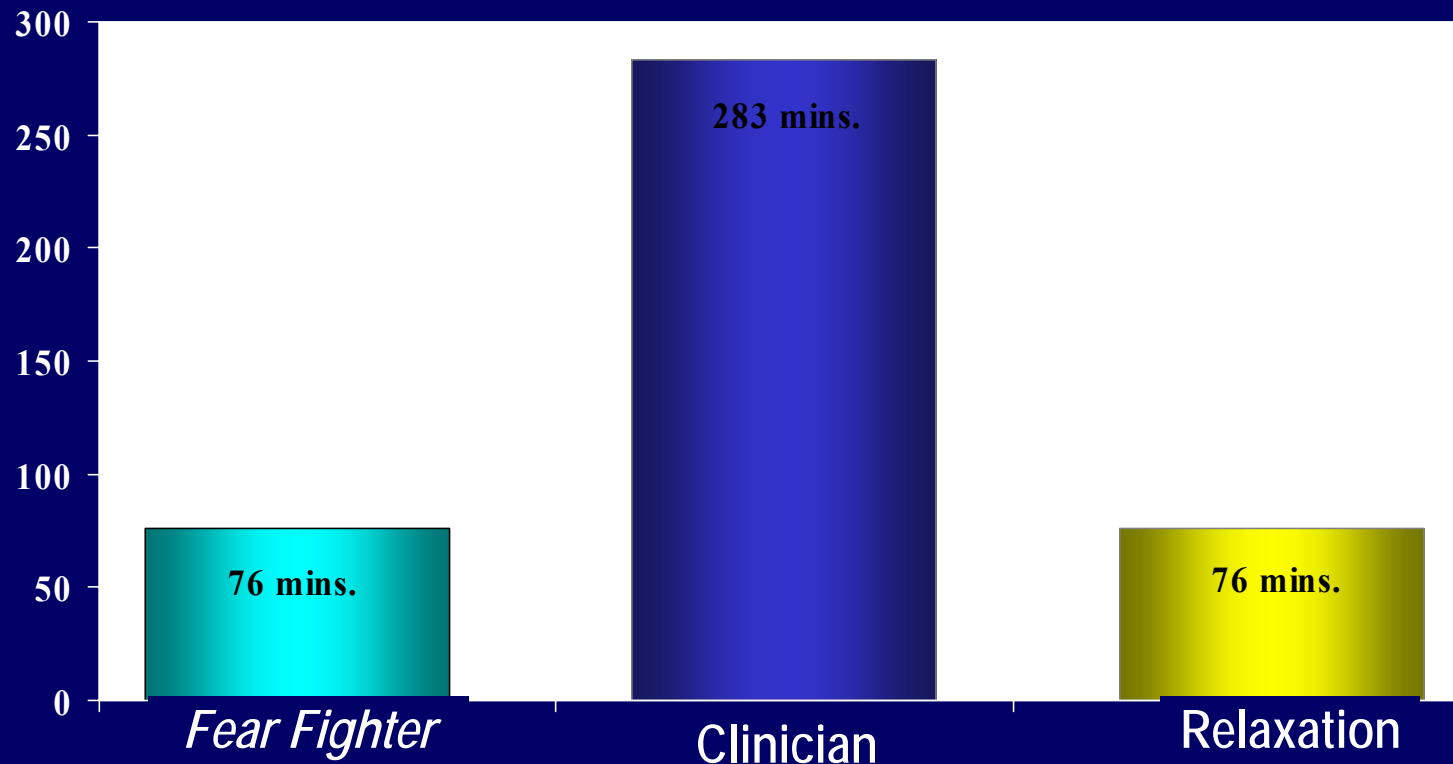
FearFighter RCT 1 *n=80*

Main Problem   *Marks et al 2004*
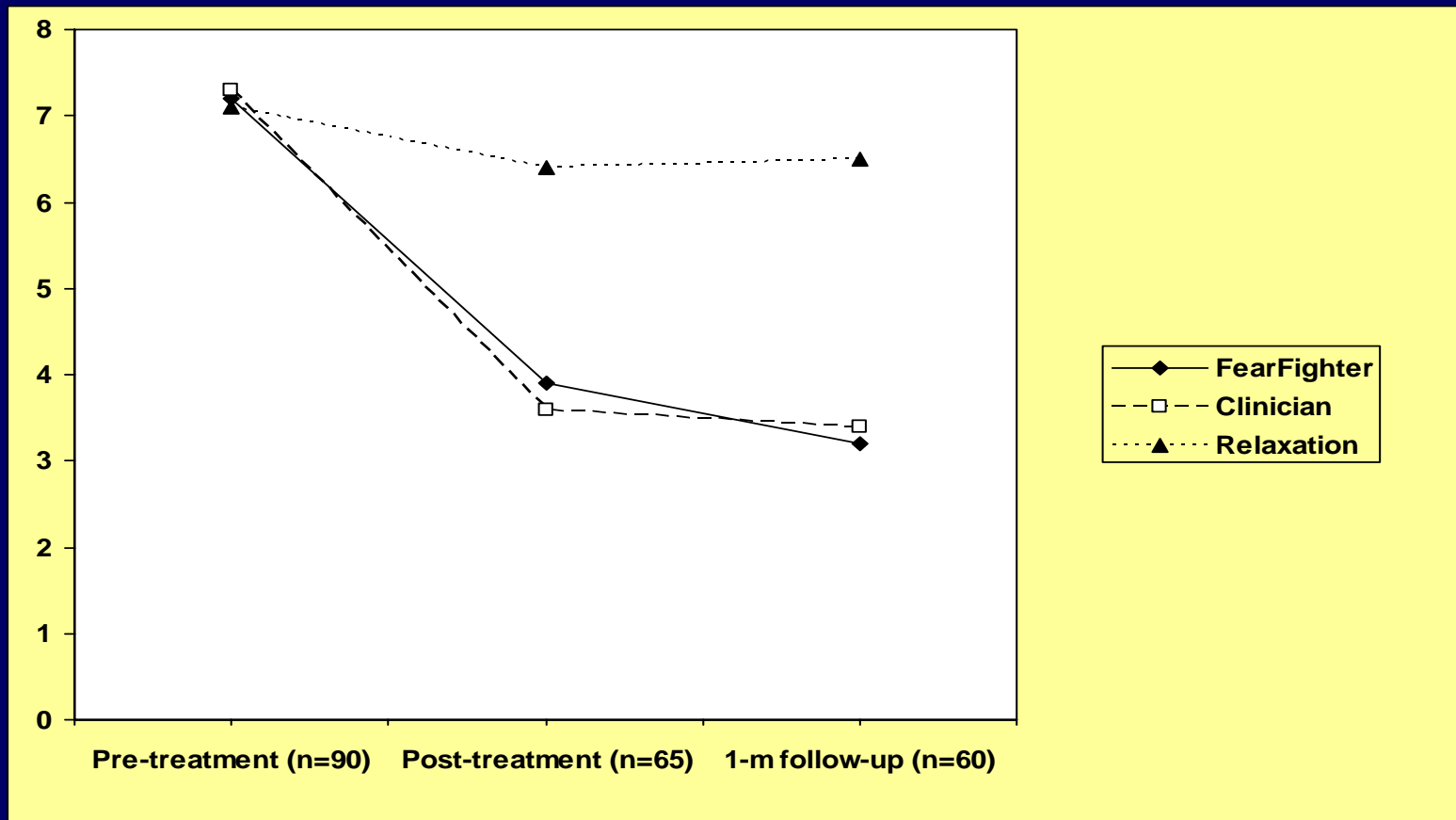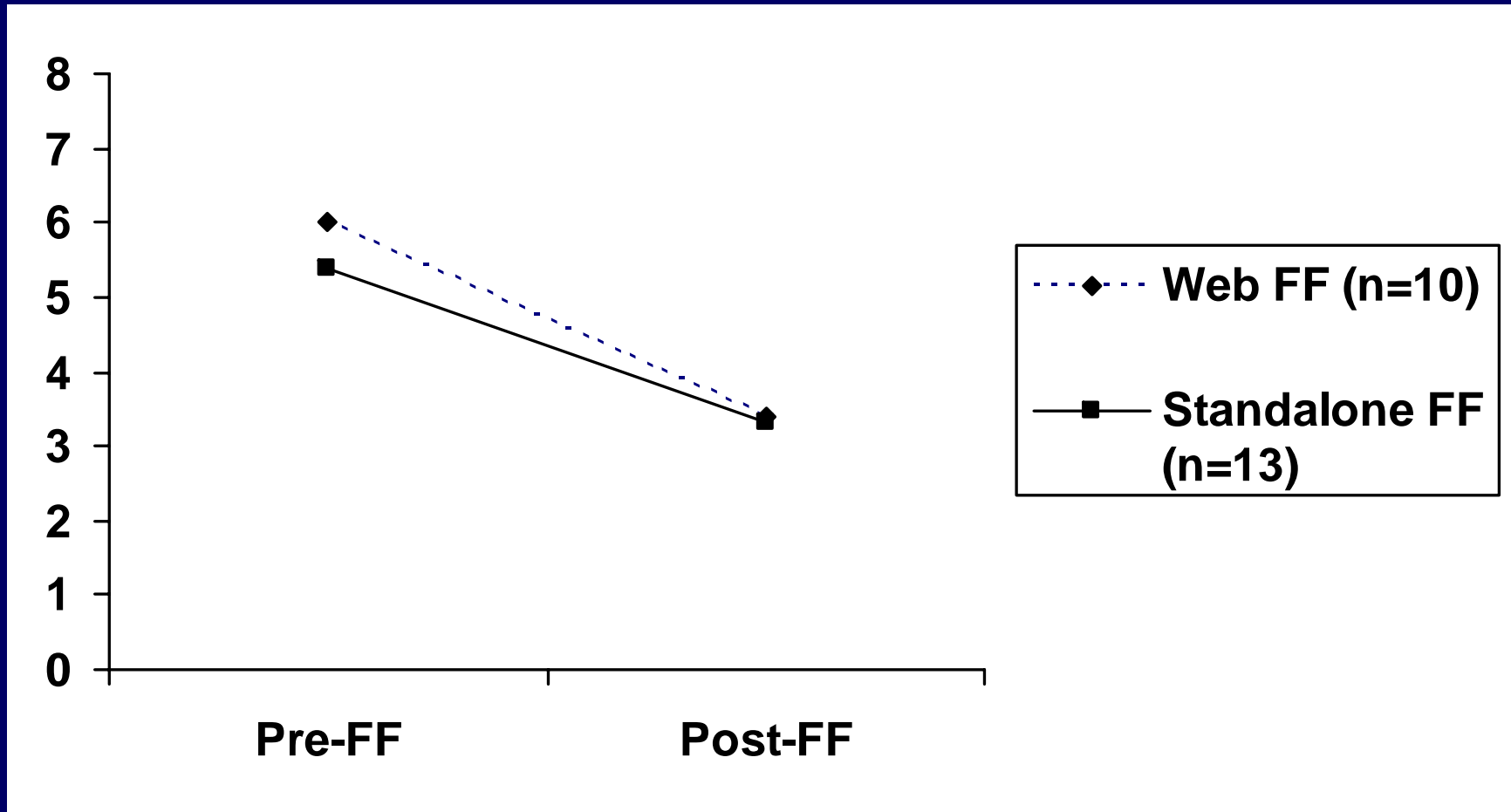
FearFighter RCT 1: n=80
total therapist contact time

Marks et al 2004

Bar chart showing total therapist contact time: Fear Fighter 76 mins., Clinician 283 mins., Relaxation 76 mins.
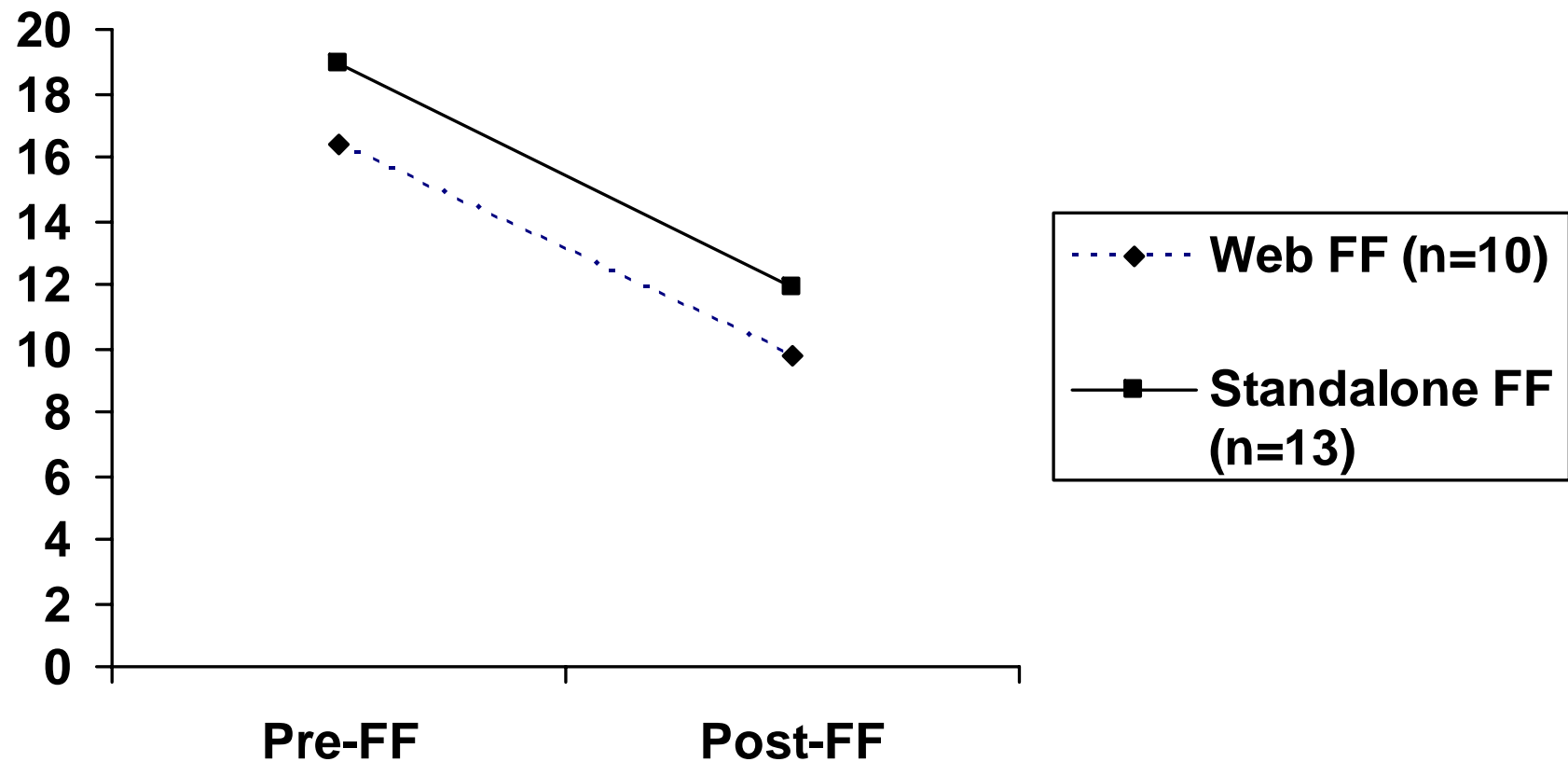
netFearFighter at home: pilot *Kenwright et al 2004*

Global phobia (Fear Questionnaire)

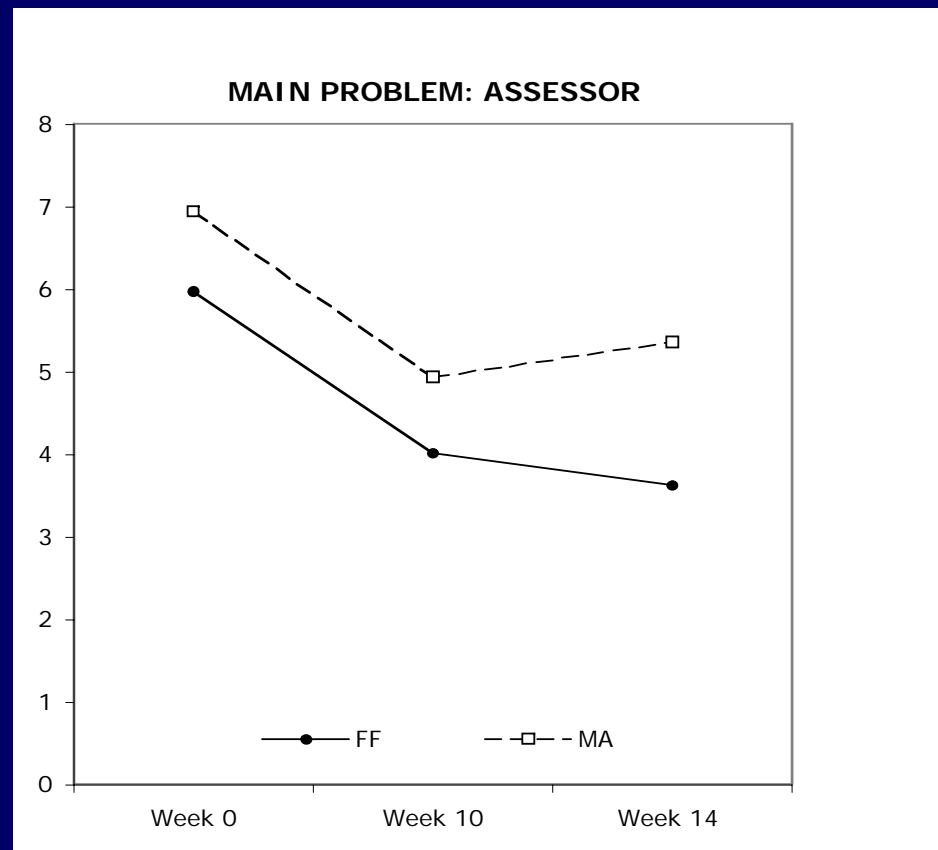# netFearFighter at home: pilot *Kenwright et al 2004*

Beck Depression

net*FearFighter* at home: RCT

Schneider et al 2005

Scottish Highlands open netFF study
Independent of *FF* developers 2006

-32 phobic/panic anxiety pts. (60% GP-, 15% self- referred), used net*FF* at home or elsewhere

-By week 10, pts. improved sig. on (*ES in italics*): FQ agoraphobia *(.95)*, social phobia *(.97) &* anxiety/ depression *(.99)*, HADS depression *(.76) &* anxiety *(.82)*, Beck Anxiety *(1.46)*, work/social adjustment *(.66)*, global improvement

-Gains similar to those with face-to-face CBT

-Gains maintained at 4.5m follow-up

National Institute for Clinical Excellence (NICE) in England & Wales *(like FDA)*

- *Feb 2006:* recommends ***FearFighter*** as an option for delivering CBT to manage panic and phobia *(1.3)*

..for stepped care of anxiety (panic disorder +/- agoraphobia, & GAD) in primary, secondary & community care *(4.3.9)*

- requires PCTs (healthcare authorities) to supply ***FF*** within 1 year

Rapid national implementation raises new challenging questions

Open studies, RCTs & meta-analyses rightly ask: *randomisat. concealed? raters blind? improvement signif. statist. & clinically? p, ES, CI, RR, SMD ..?*

BUT after above find efficacy, can't answer community-implementation issues

(CCBT easier to disseminate via net than IVR or CD-ROM)

New questions:
Cost-effective funding of CCBT dissemination, support, maintenance & monitoring?

-who pays? *patient? government? insurers?*

-licence **unit**? *per user? per region (UK Primary Care Trusts pay for unlimited FF access by all pts. from UK communities of 200,000 people upwards)? nationally?*

-licence **duration**? *year? 3 years? unlimited?*

-**personal-password access** given by? *(in UK: PCTs)*

Why not universal free access? No free lunch: Someone must pay for health care e.g. drugs, pace-makers, prostheses, professional/support time..

-CCBT systems cost $2-6 million *(medications cost $250 million)* to develop, test in repeated open trials & RCTs, apply for & get regulatory approval (*FF* began 10 years ago)

-after approval, netCCBT must be maintained & monitored

-helpline user-support: *?only 15% of usual face-to-face CBT time*
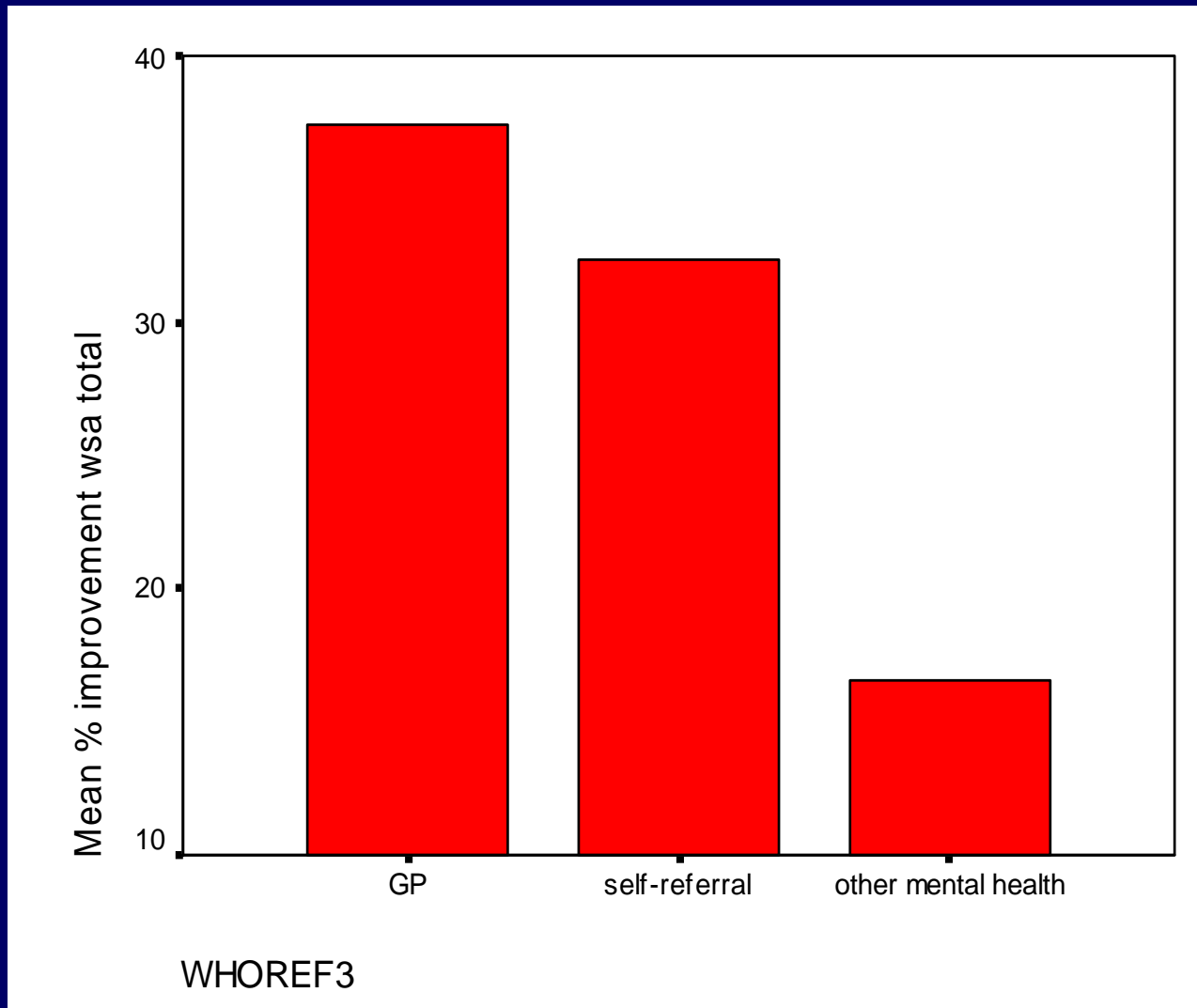
if no support: attrition often 70% to 99%

New questions:
Is CCBT best as 1st step in health care?

-↑ completion & gains if 1st than later step in care

-early referral best by primary care staff or client

-↓ GP referrals to more costly secondary care

Early referral to CCBT clinic ↓ by 80% total GP referrals to secondary mental health care
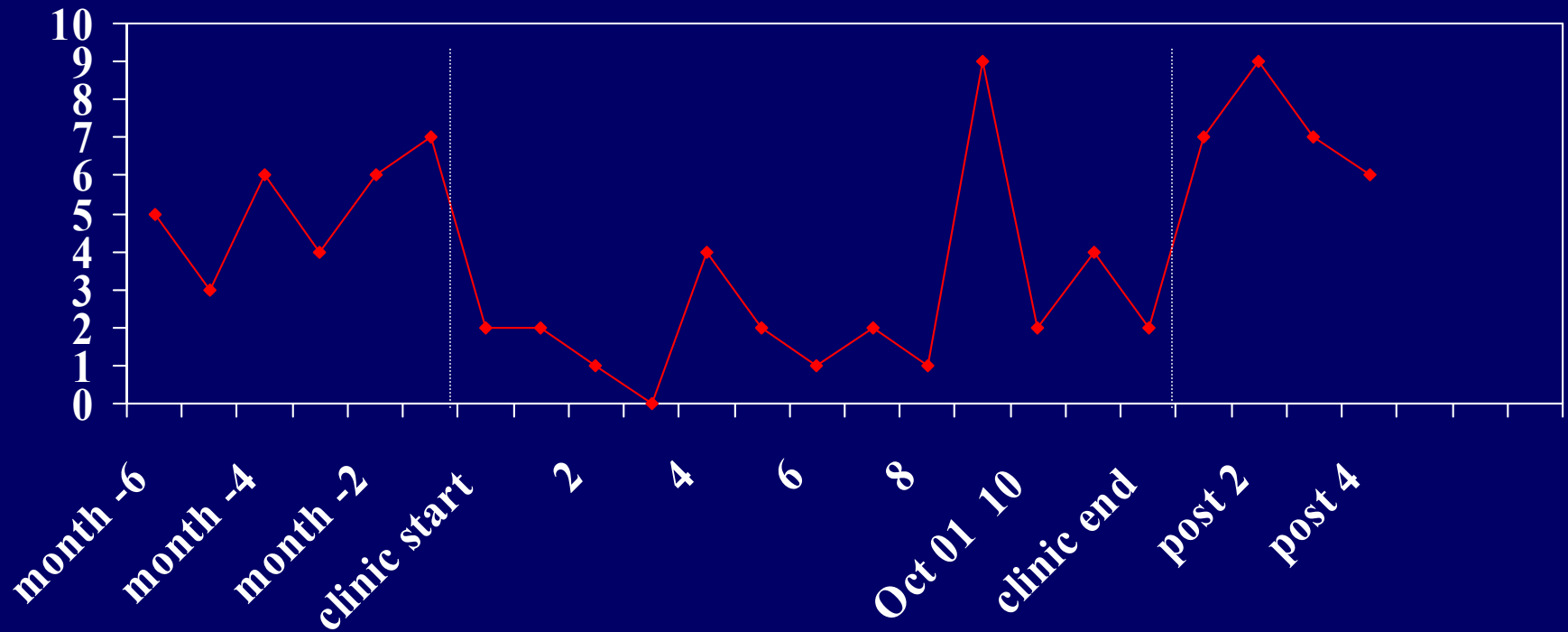
New questions: Screening: any? when? how? training?

-if no screening: *likely huge attrition, low gain*

-screening by ?questionnaire *by net, email or post* then ?live *by phone or face to face?*

-who should screen & monitor that?

-training of screener: *can be brief*

New questions:
CCBT uptake & outcome

-of total estimated no. of sufferers in region & nationally: *% referred, start, complete CCBT?*

-factors affecting above? *publicity to professionals & public, type of support, features of sufferers ..*

-clinical/social/cost-effectiveness outcome? *impact on user, family, health care use..*

-can community-wide CCBT free for users ↓ chronicity & prevalence of disorder/s?

SCREENING QUESTIONNAIRE 16 Feb 2005
Computer-aided self-help for panic/phobia *(Shortened from original)*

Your completing this form will allow us to judge if *FearFighter* will suit you. Your answers will be **strictly confidential to staff**.

Name *Mary*   Age: *61*   X Female   Occupation: *bookkeeper*

1. Can you briefly describe your MAIN PROBLEM/S in your own words? *Can't fly or be in enclosed situations e.g. lifts, train toilets, cars, or anywhere similar unless door is unlocked. Coaches OK*

2. How long have you had the above problem/s? *45 years*

3. Did your problem start after a specific event or situation?
X YES   NO   If yes, please describe that briefly: *?After having a tooth extracted when the dentist used gas & air to anaesthetise. I remember feeling absolute terror & trying to remove the mask, as clearly as if it happened yesterday.*

4. Do you feel anxious or worry much of the time? YES   *X* NO

5. Do you avoid any objects/situations/places/events/people because they make you anxious? *X* YES   NO   If yes, give examples:
Avoid anywhere I will be shut in a confined space

6. Do you check, do things repeatedly, or carry out rituals, in either thought or action, more than most other people do? YES   *X* NO

7. Choose a number from the scale below to show how much you are troubled by feeling miserable or depressed: *claustrophobic*   **X**

0 -------- 1 -------- 2--------- 3 --------- 4 --------- 5 --------- 6 ------- 7 ------- **8**

| Hardly at all | Slightly disturbing/ not really disabling | Definitely disturbing/ disabling | Markedly disturbing/ disabling | Very severely disturbing/ disabling |

8.What things bring you down or make you feel miserable and depressed? *I cannot drive since being locked in a car which I couldn't get out of. My life is terribly limited because of my claustrophobia. I long to fly and visit interesting places and family who live abroad.*

9. Has you recently thought of harming yourself or taking your own life? (please choose a number on the scale below)

   X

0_____1_____2_____3

| Definitely not | Has crossed my mind but I wouldn't do it | I seriously considered it but I stopped myself | I would do it given the opportunity |

11. Have you any serious physical illnesses? YES   *X* NO

12. Do you take prescribed, or over-the-counter, medication/s for either physical or mental health problems? *X* YES   NO
bendroflumethiazide 1 x 2.5mg daily to control raised blood pressure

13. Do you use illicit drugs/substances? (this information is strictly confidential)
                                        YES   *X* NO

14. How much alcohol do you drink a week altogether? *7 glasses of wine*

15. How much might computer-aided self-treatment help people to overcome problems such as yours?   **X**
0 --------- 1 --------- 2 -------- 3 ---------- 4 --------- 5 --------- 6 --------- 7 --------- 8
Won't help   Slightly   Moderately   Quite a lot   A great deal

16. How much of your treatment would you prefer to be guided by a therapist and how much by a self-help computer-system?

                               X

100%	**75%**	50%	25%	0%
computer	computer	computer	computer	computer
self-help	self-help	self-help	self-help	self-help

0 ---------- 1---------- **2**---------- 3- -------- 4 --------- 5---------- 6 --------- 7 ---------- 8

0%	25%	50%	75%	100%
therapist	therapist	therapist	therapist	therapist
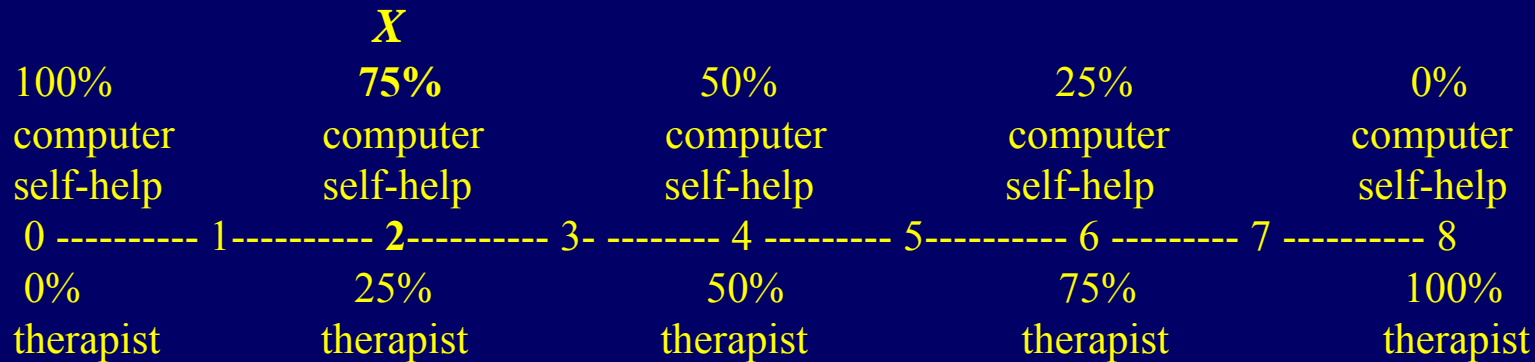
17. If you overcame your problem, what would be important for you to be able to do, that you cannot do now?   *Fly & use lifts*

18. How much would your life change for the better if you overcame your problem?   *X*

0 --------- 1 --------- 2 --------- 3 ---------- 4 --------- 5 --------- 6 --------- 7 --------- 8

Not much   Slightly   Moderately   Quite a lot   A great deal
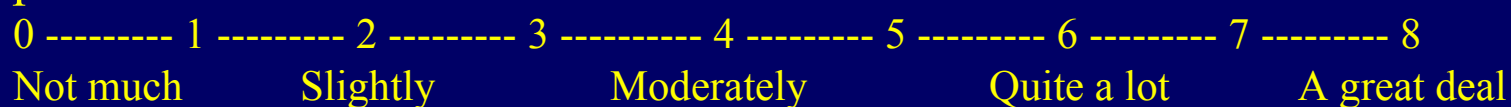
19. Part of a self-help program involves spending time carrying out daily homework tasks. Could you do this? *X* YES   NO   If yes, how long would you be prepared to spend carrying out these tasks each day?   *3 hours*

New questions
Brief support for netCCBT users

- duration? *total of ≤1 hour in all over13 wks by helpline, email, SMS*

- scheduled or on demand?

- by whom? *?anyone empathic who's used the CCBT system/s as a `pretend patient' & learned to answer users' frequently asked questions*

- from where? *local, regional, national?*

- training duration for supporters *?3days per CCBT system supported*

FRENCH PATIENT IN FRANCE   MSN chat messages
(Stuart = supporter)

27/02/2005 *16:17 Stuart pasted to Sylvie her problem on Screening Questionnaire:* "In 2003 a problem of anxiety and panics recurred which I last had at least 15 years before and which had been almost completely resolved. I was travelling in my car on the motorway; my husband was driving. Suddenly a terrible panic appeared, and I could not breathe any more and this got worse over time. My lungs felt blocked"

31/03/2005 *09:35 Stuart to Sylvie*   Hi Sylvie: How are you getting on with *FF*?

09:35 Sylvie to Stuart   Hi Stuart! **well, …I am working slowly but surely!**

09:36 Stuart to Sylvie   Excellent: its a long haul

09:37 Sylvie to Stuart   **Yes you're right! I have many different triggers so I think it will be long. And I don't expect to solve each problem in one week, for some of them it will not be possible as I need somebody to help me regularly and I need to set up a certain "organisation" in that case**

31/03/2005 *09:38 Sylvie to Stuart* **My first trigger was to try to bear to stay at home alone long enough. And I am working on it**

09:38 Stuart to Sylvie For each trigger you usually need about 10 practices on goals to resolve it, each one being a little harder. The good news is for each success other triggers often go away too. But you can never say which ones! Bon Chance!

09:39 Sylvie to Stuart **Well ! I hope it will be the case for me! ……….**

BTSteps RCT 2: Scheduled phone support enhanced OCD outcome *(n=44,* p<.01)

Kenwright et al 2005
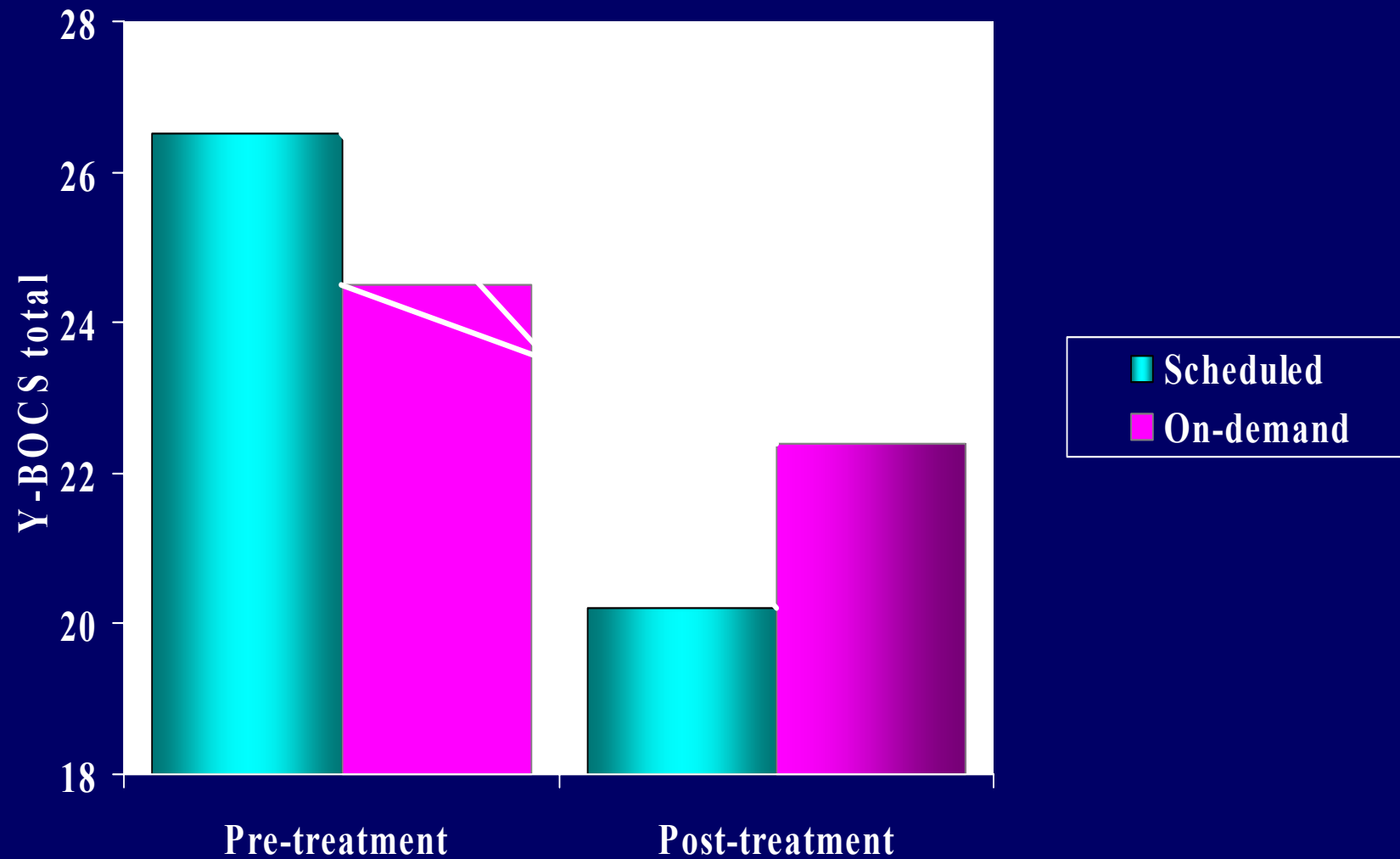
New questions: How to track wide-scale implementation of netCCBT?

-number: referred for CCBT? screened? given access? starting?   completing?

-time from referral to: each stage above?

-users' improvement in: main problems? work/social adjustment? healthcare resource use?

-brief live support: by whom? same supporter each time? scheduled/on demand? mean total time per pt? content?

-perceptions: by users? staff? community?

CCBT speeds not only self-help but also professional education & research

-in 2 RCTs, *FF-education* ↑medical students' & nurses' knowledge of panic/phobia & CBT almost as much as did face-to-face teaching

McDonough & Marks 2002; Gega et al 2005

- CCBT enhances research into process & outcome