

They may sound like children's TV characters, but RUF, HUG and Morph represent a new wave of British user groups whose rise has been swift and impressive. **Max Daly** speaks to the new kids on the block

More answers than questions

RUF (READING USERS FORUM)



"Some user group leaders just want notoriety, to be a rebel putting a spanner in the works, and that's no good. We're not just complaining, we're offering solutions," says John Howard, co-ordinator of the 10-month-old Reading Users Forum.

RUF was formed in July 2004 following the collapse, due to mud-slinging and in-fighting, of the short-lived Reading Users' Union. The most pressing problems the new group faced were long waiting times for treatment and an overly bureaucratic prescription system known as the four-way agreement. It meant prescriptions had to be signed by the user, their GP, a pharmacist and a specialist service before it could be used. If anyone dropped out, a replacement signature had to be found otherwise the prescription was useless.

"The system was punitive and it effectively stopped some people accessing treatment," says Howard, who got some advice from the Oxfordshire User Team (OUT), a well-established user group paid by the NTA to help out smaller groups in south east England. A meeting was set up with the head of the Primary Care Trust, the joint commissioning manager and a senior GP. "I introduced myself and RUF, explained the problems users in Reading were facing and how we wanted them dealt with. I made it clear we were not happy. I got a very positive response.

"I think we got the message across because of our persistence, professional attitude and the fact we made valid points and knew our stuff," says Howard, a full time volunteer on benefits who works with four others at RUF. "We got an invite to sit on other meetings and we quickly became a powerful and respected force in Reading. And this was not just tokenism." RUF represents users by speaking to them at drop-in centres and in the streets and handing out questionnaires. "We

have a big peer network of people. If services want to know anything specific about drug use they will go through us," says Howard.

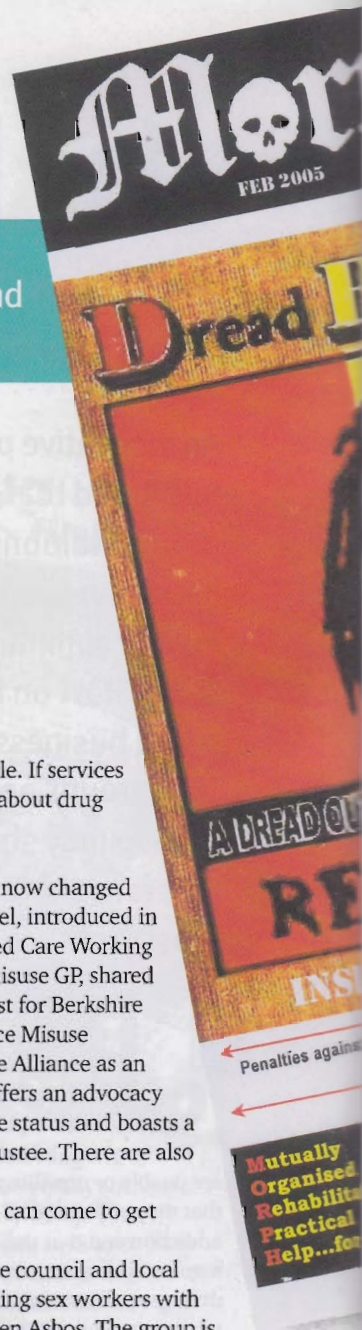
The four-way agreement has now changed to a shared care agreement model, introduced in April. RUF now sits on the Shared Care Working Group along with a substance misuse GP, shared care advisor, the head pharmacist for Berkshire and the West Berkshire Substance Misuse Manager. The group, used by the Alliance as an example of best practice, now offers an advocacy service, is applying for charitable status and boasts a former mayor of Reading as a trustee. There are also plans to set up drug surgeries where anyone – families, carers, can come to get information and have a chat.

RUF is campaigning to get the council and local media to stop naming and shaming sex workers with drug problems after they are given Asbos. The group is currently providing support for several sex workers who have appeared in the press. RUF has also asked the editor of the local paper, the *Reading Evening Post* to stop using the word 'junkies'. "We want to create a better understanding and attitude to the drug problem with the wider community and to debunk a few myths about drug users. If drug users are treated with a bit more compassion and understanding then we can move on."

HUG (HERTFORDSHIRE USER GROUP)

Like RUF, HUG rose from the ashes of a previous user group, the Hertfordshire User Team, which was wound down after it was alleged members were fiddling down expenses. Also like RUF, the group received a helping hand, this time from its local DAT, which funds it, and more experienced user campaigners. HUG was founded in September 2004 with the help of Bill Nelles.

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DIY news: Morph's monthly newsletter, *Morphin'*

"Users were complaining of waiting times, lack of consultation on scripts, sub-therapeutic dosing, bad key workers, non-existent care plans – there were a myriad of problems," says chairman Jimmy Grieve. "All the health professionals were there but treatment was well below par."

"Our philosophy is that advocacy is the best way to sort this out," says Grieve, a now abstinent ex-user who has a family. "The DAT have been very helpful and reactive. If there is a problem with the local GP or key workers we highlight it to the DAT and it looks at how staff are recruited. We look at what's going wrong at the bottom and make sure it is sorted out at the top."

The group is trying to tackle the problem of younger more chaotic users who don't engage in services and are not listened to, by canvassing for ideas on the streets on what they need. HUG runs training for GPs, peer education courses on blood borne viruses, harm reduction and advocacy initiatives and overdose awareness workshops run by paramedics. It is involved in formulating job applications and job interview techniques for Hertfordshire drug workers. HUG members, all unpaid volunteers, attend NTA regional meetings and are on the National Users Advisory Group. "We are all over 30 and have a lot of experience of the prescribing and criminal justice system. I work 12 hours a day. We are all

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committed, passionate and know the system intimately. We've all fallen foul of it and all benefited from it. We are not anti, we are positive. We talk common sense."

MORPH (BASED IN SOUTHAMPTON)

"We started Morph in January 2004," says one of Morph's two co-founders Simon Parry. "Four of us started meeting-up for two hours every Monday afternoon at Southampton's voluntary services building: me and my partner Sue Tutton (both six months into Subutex scripts) and two blokes on DTTOs. The manager of the city's mobile needle exchange put us all in touch and left us the O.U.T. *User Involvement* manual. We'd all been heroin addicts for about 10 years."

"We decided we wanted to try and do something about the four month wait for a script at the time. We worked out how much money a heroin user would have to raise (about £2,500) and how many injections it would need (700) to get through this wait. This was why we started the group. I had a four month wait and figured this was ridiculous and people could easily die or end up in jail in that amount of time. I wanted to try and do something about it. We introduced ourselves to the local service provider by letter and arranged the first of now regular monthly meetings with their team leader."

"A few weeks in, we were told about a dodgy batch of heroin in the city that was killing people. We decided to put out, *Morphin'*, an A5 single-sided bulletin with the warning and some stuff about the group. A few weeks later there was another warning, so since then we've brought out *Morphin'* roughly once a month, printing off more and more each time. It is now a 16-page affair, we've printed-off 600 of the latest one – Number 10 – and our mailing list alone is about 480!"

Morph now sits on the Drug & Alcohol Reference Group, Treatment & Care Sub-Group, Hampshire Advocacy Regional Group, the DAT, and the NTA's South East User Forum. "We started and host a Hampshire User Forum and are working on the Joint Commissioning Group. Our latest DAT manager is very much pro-user involvement, which is a bonus, and we are in almost daily contact with her." Morph still holds weekly meetings every Monday, is Southampton's Service User advocacy service, has organised two conferences so far on user groups and prison detox and put on a free live music all-dayer in a local park. The group has set up regular outreach 'slots' at local services to gather users' views and ensure everyone is getting the treatment they require and is in the final stages of organising hepatitis C peer-support workshops. OD prevention classes are in the pipe-line. ■